People Concerned for the Unborn Child

"Pennsylvania's oldest and largest grassroots pro-life organization."

June 2, 1983

Mr. Morton Blackwell
Special Assistant to the President
The White House
Washington, D. C. 20500

Dear Mr. Blackwell:

Many thanks for your prompt attention to our request for a message from President Reagan to the Greater Pittsburgh March for Life Rally which took place on May 28. It was a fine message from the President and most enthusiastically received by the 5,000 people who heard it read. We truly appreciate the important part you played in bringing all of this about. I'm enclosing several pictures and articles from the March which should be of interest to you.

I also thought you might be interested in something that happened here in Pittsburgh on April 6th, the day that the President came to our city to speak at the Hilton Hotel. The newspaper accounts - while making much of the hostile crowd of unemployed people who were protesting outside the hotel - nevertheless, all noted that there were representatives of People Concerned for the Unborn Child at the hotel with a welcome banner. One of the women even had her finger broken as the banner was snatched from her hands by a steelworker.

Perhaps there will be some opportunity to bring this to President Reagan's attention as we want him to know that he definitely has friends in the pro-life movement in Pittsburgh. People Concerned for the Unborn Child is the oldest and largest pro-life group in the state with 9,000 members in the Pittsburgh area. We are prepared to enthusiastically work for President Reagan's re-election should he choose to run.

Again, our thanks for your help in making our Rally a success.

Sincerely yours,

Mary Winter

Mary Winter, Executive Director

MW.ds
enclosure

1760 POTOMAC AVENUE • PITTSBURGH, PA. 15216 • 412/531-9272

Greater Pittsburgh March For Life
1760 Potomac Avenue
Pittsburgh, PA 15216
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FOR IMMEDIATE RELEASE June 3, 1983

The 5th Annual Greater Pittsburgh March for Life drew an estimated 5,000 people on May 28th for a march through downtown streets to a rally at Point State Park. The theme of this year's march was "In Memoriam: 13 Million Killed By Legal Abortion." The March itself was without bands, cheerleaders and floats. In keeping with a theme of mourning on the Memorial Day weekend and the millions of children killed by legal abortion, the crowd walked in silence except for the beat of drummers marking a cadence.

At the rally people were greeted by Pittsburgh's Mayor, Richard Caliguiri. A Proclamation was issued by the Commissioners of Allegheny County declaring May 28th "Respect Life Day" in Pittsburgh and commending the people for their efforts to restore a respect for life.

The rally was broadcasted live over WPIT Radio by the rally's Master of Ceremonies, Dick Hatch, WPIT-Talkshow host. The main speaker, the Reverend John Guest, Rector of St. Stephen's Episcopal Church, spoke of the need to change hearts by converting people to God so that they will be willing to accept new life as God's gift, even when that life is not convenient, burdensome or unplanned.

Mrs. Anna Marie Grubbs, the March Coordinator, presented the annual "Life Leader's Award" to Attorney Nellie Gray who has coordinated the annual National March for Life in Washington, D. C. for the last 10 years.

At the end of the rally, children released 1,000 red balloons with a "Protect Life" slogan and a rose imprinted on each. Inside each balloon was a paper on which was printed a pro-life message offering help to women with problem pregnancies and a prayer. This symbolized the prayers going up to God and the

(More)

pro-life message going out to the world. As the balloons floated high into the air, the crowd sang the "Battle Hymn of the Republic" and taps were played. The day's events were co-sponsored by 60 pro-life/pro-family organizations from the Pittsburgh area and nearby parts of Ohio and West Virginia.

People Concerned for the Unborn Child, Pennsylvania's oldest and largest pro-life organization, was the group coordinating the event.

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Public Relations, Chairman

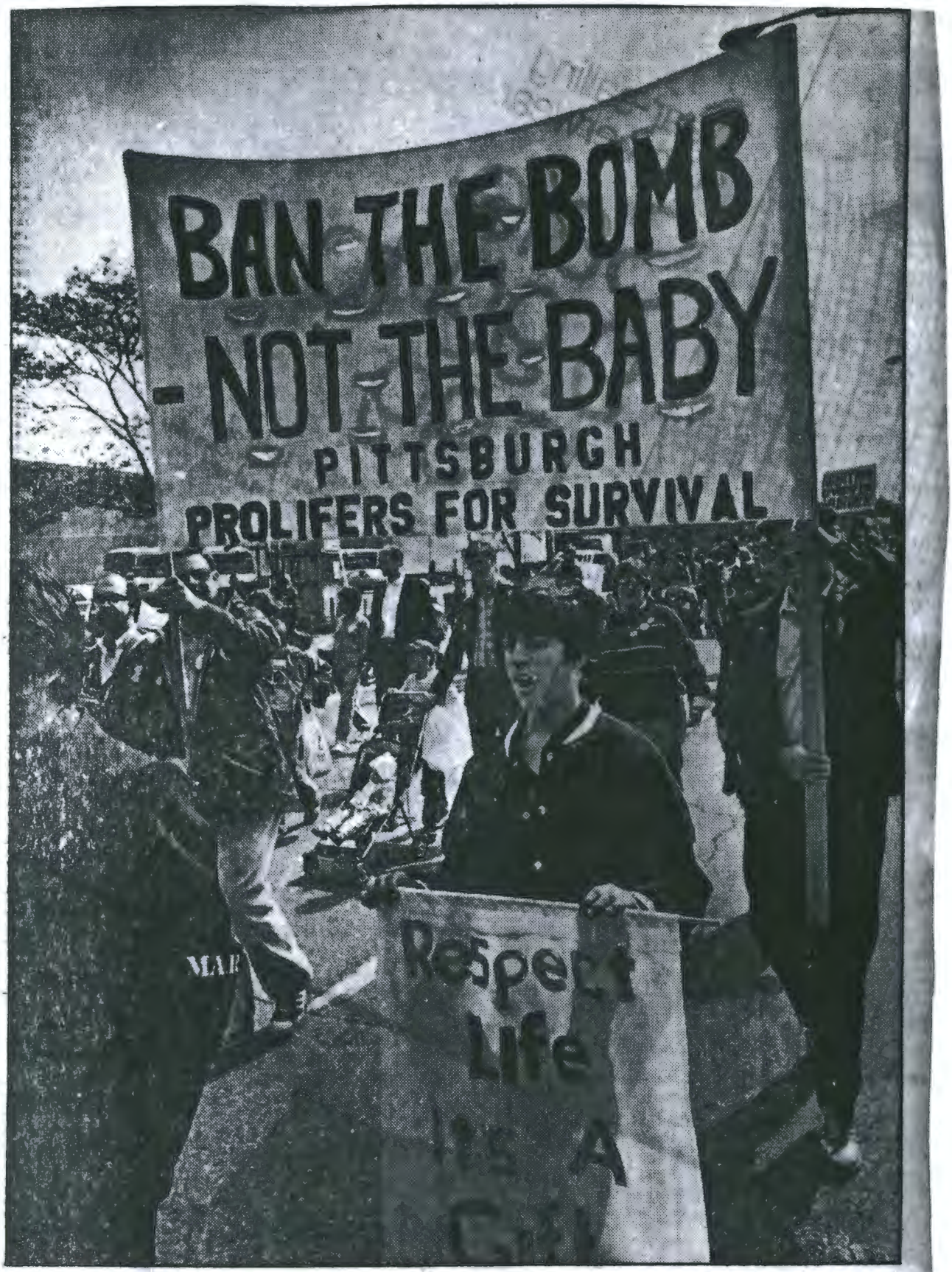

MARCH FOR LIFE

5/20/83
Post-Gazette

Harry Coughanour / Post-Gazette

Joshua Finkbeiner, 4, of the North Hills marches with about 5,000 other people in the fifth annual Greater Pittsburgh March for Life held Downtown Saturday. Sixty anti-abortion organizations sponsored the event.

Pittsburgh Press, Sun., May 29, 1983



Press photo by Andy Starnes

Downtown March for Life

About 5,000 people from 60 pro-life, pro-family organizations from the Tri-State area turned out yesterday for the fifth annual Greater Pittsburgh March for Life, winding through Downtown to Point State Park and a rally during which Nellie Gray, president of the National March for Life in Washington, D.C., was presented the 1983 "Life Leader Award." Principal speaker at the rally was the Rev. John Guest, rector of St. Stephen's Episcopal Church, Sewickley, and president of the National Institute of Christian Leadership.

Pittsburgh Press 5/27/83

Pro-Lifer Nellie Gray Brings Her Crusade Here

By DEBORAH DEASY

She is like a thorn in the side of a nation, the mouth of a movement, a 58-year-old lawyer from Washington, D.C. with an accent from Texas.

It's been 10 years since Nellie Gray coordinated the first March for Life, the national demonstration which still brings thousands of anti-abortionists to Washington, D.C., every Jan. 22.

Bundled against inevitable cold, her crowds still come in buses — 700 this year — from states across the land. Carrying signs and beating drums, they march from Washington's Ellipse to Capitol Hill. They snarl traffic and jam bathrooms in the museums along Constitution Avenue, but street vendors like them because they buy a lot of hot dogs and soft pretzels.

They'd prefer to march in warmer weather, but it was Jan. 22, 1973, when the U.S. Supreme Court ruled on a case called Roe vs. Wade and decided that abortion is a private matter between a woman and her doctor.

"This is a day of infamy for the whole world," says Miss Gray. "And it is going to be memorialized as such.

"I'm not really the one who started the march and everything."

The idea originated with a handful of active pro-lifers from Long Island, N.Y., who'd fought for anti-abortion legislation in New York in the late '60s.

"It's just that they met in my house and they needed an administrator and here I was. I kind of fell into the job, you know?"

As volunteer president of the March for Life, Miss Gray still works 12 months a year, without pay, organizing the march and trying to change the law of the land. The march is a volunteer effort.

"We have Atheists for Life, Libertarians for Life, you have Lutherans for Life and, I don't know ... Baptists for Life. This is the reason that the pro-life movement cannot be characterized as anything other than a broad-based, grassroots position."

She'll be in Pittsburgh to receive the first Life Leader Award at noon tomorrow in Point State Park, rally site for the fifth annual Greater Pittsburgh March for Life, which is giving the award.

Nellie Gray
Getting award here tomorrow.

The march will start at 11 a.m. at the Civic Arena and proceed to Point State Park where Miss Gray will join the principal speaker, the Rev. John Guest, rector of St. Stephen Episcopal Church, Sewickley.

There will also be a prayer vigil tonight from 8 to midnight at Women's Health Services (which performs abortions) at the Fulton Building, Downtown.

"I think we are all inspired by her stick-to-it-ness. We realize it will be a long struggle and we're willing to make the sacrifices required," says Mary Lou Mahon, publicist for tomorrow's march. "We have so many more groups co-sponsoring the march, our base seems so much broader; it seemed like an opportune time to single out someone who has been in the forefront of the movement since the Supreme Court decision of 1973."

A native of Big Spring, Texas, Miss Gray served as a WAC corporal and secretary in World War II before graduating from Texas State College for Women in 1949 and taking jobs in the U.S. Departments of State and Labor. After attending night school, she received a law degree from Georgetown University in 1969.

Never married, she works out of the home she purchased 20 years ago.

"I've already had a hate sign painted on my doorstep by the abortionists," she says, reluctant to divulge the location. She lives off the annuity she receives as a retired federal employee.

She never planned on this abortion crusade.

"The whole issue of abortion was coming up in the late 1960s in New York. But I have to admit I didn't think very much about it."

Then a 1970 court decision cleared the way for abortions, in the District of Columbia, to save the life and health of a mother.

"Abortion just sprang up overnight in the District of Columbia," she recalls. "I was so appalled by the thing that I went down to listen to some of the hearings in the city council and I couldn't believe my ears — that people were coming in and telling how wonderful abortion was and that they needed clinics. I did not understand abortion. I went to some doctors and said, 'Will you tell me what this thing is?'

"I felt, as cases started up, that certainly the Supreme Court would rule people can't go around killing babies. But when the court did not so rule, I was really appalled.

"I was working at the time, and trying to do some pro-life work on the side. There came an opportunity for me to retire from the federal government. I had decided to go into private law practice and do right-to-life work on the side. I never did go into private law practice. I do right-to-life work full time."

It costs a little more than $100,000 to stage the annual March for Life, with printing, postage and advertising costs taking the biggest chunk, though some television stations have refused to sell spots announcing the march.

And there are the red roses sent to Congress every Jan. 22.

Working late into the night sometimes sometimes early into the morning, Nelli Gray puts in varied days filled with cross country phone calls and the tedious busi ness of getting permits and lining up speakers for the annual march. Conven tions and appearances like the one her tomorrow take her across the country.

Primary goal of today's pro-life move ment is passage of a "human life" am mendment to the Constitution, she says Four proposed versions are before con gressional committees now.

"Undoubtedly something will come ou on the floor of the Senate sometime this session.

"The wording that we need to put in the Constitution is to assure that the person hood of every man, woman and child, born and preborn, shall be protected by the Constitution.

"Whenever people can use other human beings they will, and a society has to tell them, you may not. They may not use the blacks. They may not use the Jews. They may not use the babies. They may not use the aged or the handicapped or the ill. We are going to protect all human beings born and preborn, equally."

After 10 years of battle, "I do not intend to give up," she says. "Also, I do not intend to become a professional pro-lifer. I intend to get this job done and done well.

"I have a number of other things to do with my life besides being a professional pro-lifer. I feel it is a great imposition on me and all the pro-lifers that we have to defend the right to life of anybody, including innocent little babies when our Constitution should be doing that and the government should be doing that."

Beaver County Times

4/7/83

Times photo by Pete Sabella

The Beaver County contingent takes its place in the Reagan protest.

Reagan protests fall on deaf ears

By SANDRA SKOWRON
Times Staff

About 3,500 jeering, chanting protesters massed near the Hilton Hotel to "welcome" President Reagan to rainswept Pittsburgh Wednesday, but few, if any, saw the chief executive.

As the crowd huddled across from the hotel's main entrance, Reagan and his entourage were whisked into and out of the well-guarded building through an underground entrance, frustrating demonstrators.

While Reagan addressed the National Conference on the Dislocated Worker, a group of the protesters angrily chanted — among the more tame slogans — "We want Reagan" and, at one point, "We want Hinckley," a reference to John W. Hinckley Jr., who shot Reagan in March 1981.

Having missed the president's notice, some demonstrators taunted police and any person or thing that looked official. Several tussled briefly with officers who were trying to clear a lane of traffic along Liberty Avenue.

Overall, there was little violence, possibly because police dogs were used to patrol the area. There was at least one arrest.

The few Reagan supporters were a solitary lot. When a group of pro-life activists unfurled a banner reading "Welcome Mr. President," the crowd erupted in a chorus of boos.

Moments later, a man raced from the crowd and struggled for the banner, ripping it in two. He then returned to his place, triumphantly waving his piece of cloth before tossing it into the mud.

Dave McAlpine, Baldwin, said he didn't even notice the pro-life reference on the banner. "When I saw it — 'Welcome Mr. Reagan' — I just saw red," McAlpine explained later. He is laid off from U.S. Steel's Irwin Works.

McAlpine left five women representing Pittsburgh's chapter of People Concerned for the Unborn Child with bruised fingers and a tattered remnant of their sign.

"We're here to show our support for the only president who has supported our position," said Doris Grady of Shadyside. "I think that actions like that just indicate that they don't have any respect for women, if a guy would do something like that."

"We're out here to defend life," added Mary Meenan, Beechview, "and support the president on the abortion issue."

The sign-waving crowd began to trickle into Point State Park, across from the Hilton Hotel, about 9:30 a.m., more than three hours before Reagan was scheduled to speak.

Some said Wednesday's steady rains, which started as misty drizzle, robbed the crowd of larger numbers.

Most of the drenched demonstrator were unemployed steelworkers, min workers and laborers; they were joined b groups representing students, women, an black, anti-war and anti-nuclear interests.

For the jobless, the protest provided safety valve for pent-up anger and frustra tion.

"No, I don't think the president will n tice," said Rhoda Linderman of McKee port, laid off from U.S. Steel's Nationa Works in McKeesport a year ago. "But will help us get rid of our frustrations. Wha else can you do? There's an awful lot of an ger down here."

"The only thing we can do is prote and vote," said John Bjonberg of Irwin who, minutes later, accidentally steppe too close to a police dog and came awa with a three-inch hole in his jeans.

(See Protest Page A8)

(Continued from Page A1)

Some suspected, even before Reagan arrived, that he would avoid them.

"Oh, he won't notice us, 'cause he's going to fly right in there and fly right out," said Darryl Crite, of Pittsburgh's Northside, a member of ACORN — the Association of Community Organizations for Reform Now.

Following Reagan's arrival, the crowd split into two groups. The boisterous demonstrators centered themselves near the Liberty Avenue entrance to the hotel, shouting slogans and obscenities. Another group gathered around a platform in Point State Park to hear a variety of labor and social activists.

Protesters came from three states — Pennsylvania, West Virginia and Ohio — and arrived by chartered buses, car pools and on foot.

A large contingent from the Mon Valley congregated at the U.S. Steel Building on Grant Street and then marched to Point State Park.

The unemployment rate is 16.2 percent in the four-county Pittsburgh area, which has been called the "Rust Bowl" because of abandoned, rusting steel mills lining the Allegheny, Monongahela and Ohio Rivers. Beaver County's jobless rate is 23.1 percent, fifth highest in the state.

A White House press spokeswoman told reporters on the flight to Pittsburgh that the White House was aware the trip could be confrontational.

"[Reagan] is not afraid to go into a potentially confrontational situation," the spokeswoman said, adding that the president was concerned about unemployment.

Sen. Arlen Specter, R-Pa., predicted that Reagan would receive a "respectful' reception, but he added: "If there are brickbats, we want to be there to shield him."

In his address, the president referred to the crowd only once, saying that he had come to discuss the unemployed, "some of whom are across the street venting their confusion and anger."

Among the demonstrators were two former air traffic controllers, Rick Snyder and Bill West, both of Moon Township. The two lost their jobs as a result of the air traffic controllers strike in 1981, which saw PATCO decertified as the controllers' bargaining agent.

"He [Reagan] basically made sure we couldn't get work, we couldn't get unemployment, that I'm blacklisted and that I can't get anything," Snyder said. "I think that he's going to put everyone out of work.

"I'm just here to let him know that I'm still alive..."

"And kicking," West added.

Press 4/6/83

4,000 Jobless Protest Reagan's Arrival

By NICHOLAS KNEZEVICH
And DON HOPEY

Leaden skies and steady drizzle did not deter busloads of the area's unemployed from showing up at Point State Park today to protest against President Reagan while demanding jobs.

More than 4,000 unemployed assembled in the park, holding aloft protest signs and umbrellas.

They had come from Wheeling, W.Va.; Youngstown, Ohio; Indiana, Pa.; New Stanton and the hard-hit Mon and Beaver valleys.

Most of the protesters streamed over the Fort Duquesne Bridge from the Three Rivers Stadium parking lot and from various other North Side drop-off points.

Another contingent of about 500 assembled at the Grant Street headquarters of U.S. Steel Corp., whose mills are operating at less than 50 percent of capacity. They marched to the Point, merging with groups entering from the North Side.

Steelworkers, auto workers, electrical workers and others feeling the sting of unemployment shouted slogans demanding jobs. Placards declared: "Reagan — Unwanted."

Had it not been in a serious mood, the assembly could have been mistaken for a picnic crowd under the drizzly skies.

The five-piece Shawn Thomas Peace Band entertained the restless protesters as they awaited the president's arrival. Some performed a skit, placing Reagan on trial by the "Not Ready for Unemployment Players."

When a group of anti-abortion demonstrators unfurled a 6-foot-long banner declaring "Welcome Mr. President" on the sidewalk in front of the Hilton, jobless workers booed and one of them darted across Commonwealth Place, ripped the banner in half and grabbed it from the women's hands.

Responding to the act, Mary Winter, founder and executive director of the People Concerned for the Unborn Child, said "there are issues and there are issues. We have as much right to be here as they do. We

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4,000 Unemployed Protest President's Arrival Here

(Continued from Page A-1)

hope the president would see the pro sign, as well as the negative signs."

She said she was fearful for the president's safety because of the "Reagan Wanted" signs carried by some of the unemployed. She said she recalled seeing the same kind of signs before President Kennedy made his ill-fated trip to Dallas in 1963.

"I think it was petty and childish for that man to rip down that sign. It showed a total intolerence to anyone else's opinion," she said.

Surprisingly, one of the loudest boos came from the 700 delegates to the conference on the dislocated worker as they were to be seated inside the Hilton Hotel for Reagan's arrival.

The protest arose as they were herded into long lines to pass through airport-like metal detectors.

One of the delegates looking out to the protest crowd was heard to say, "Not too many for a presidential visit, but determined, I guess, since they're willing to get soaked."

"I'm here to demonstrate against Reagan," said Andrew Sopko, 59, president of USW Local 1270 at U.S. Steel's American Bridge plant in Ambridge. "This is the worst I've seen it (the economy) in 41 years. Right now, we've got 15 people working in the plant. In 1947, we had 4,000."

Sopko said all the people have to get involved in protesting against economic conditions.

Tom Ehman, financial secretary of USW Local 7297 at Teledyne Corp.'s Latrobe plant, said only 200 of the 481 workers there are still on the job.

Ehman seethed over Reagan's attitude about retraining, stating that the president's appearance was merely political.

"I have Control Data (on the North Side), where he visited, only yesterday got new equipment. They wouldn't have got it if Reagan wasn't coming," Ehman said.

"This is not only happening in steel imports, but also in fabrication," Sopko said. "In Seattle, they're building a structure with steel from Japan that was fabricated by Korean workers. That's *our* work."

Dennis Burke, president of USW Local 7543 in Butler, said the major industries in his town are hurting.

"Butler is dying," Burke said. "We want to call Reagan's attention to the fact that we don't agree with his policies. We want to influence him to get out and see what's really happening."

Burke, 35, worked for 18 years at Spang & Co. in Butler, a well-drilling equipment manufacturer. He was laid off five weeks ago.

Burke said the government tax laws are hurting productivity and creating unemployment.

"I think the government should look at the tax laws that allow the company to make more of a profit by shutting down," Burke said. "Right now, companies are looking for big profits and are shutting even if they are making moderate profits."

Kenneth Burke, brother of Dennis and an employee for 12 years at Pullman-Standard, said America could become another Poland.

"Does Reagan want another Poland with everybody protesting?" Kenneth Burke asked. "That's what it's coming to, with everyone out of work."

James G. Camp, chairman of the Beaver County commissioners, accompanied unemployed Beaver County steelworkers to the rally and pledged the county's total support.

"We want to make Reagan aware of the problems in the steel industry by coming here to protest," Camp said. "He's here to test the political situation in this area, but we know, with employment currently at 24 percent in Beaver County, just what the problem is."

Camp, a Democrat who is seeking re-election, said Beaver County is very much interested in bringing in new, light industry to replace dying steel industry.

"I absolutely think the government should be doing more," Camp said. "It should be providing more job programs on the local level. Pennsylvania's bridge-building program could go a long way to reviving the local steel industry, if we could just get money to buy local steel for the bridge program.

"Even if we have to pay more, it would be worth it to get all the unemployed back to work."

Timothy Session, 27, of Crafton, was laid off a year ago from U.S. Steel's National Plant of the Mon Valley Works in McKeesport, said Reagan's policies are causing irreparable harm to the nation.

"You know what the signs say, 'If you stay the course, we stand to lose everything,'" Session said.

Hank Edmunds, 58, unemployed for seven months after working for 36 years at U.S. Steel's Ambridge plant, said the government has to get involved in helping the unemployed because the private sector never has.

"Reagan is taking credit for lowering the interest and inflation rates but he blames Carter for the high unemployment," Edmunds said. "It was the unemployment that brought the inflation and interest rates down. Why is Reagan trying to take credit for two of those, and not the third?

"He just can't turn his back on the unemployed. The private sector just won't help."

Before departing from Wheeling for Pittsburgh this morning, Steve Paesani, spokesman for a group of 200 calling itself the Ohio Valley Unemployed Committee, said it believes Reagan and the business community aren't doing enough to combat unemployment.

"We want to express our displeasure with the people who will be at the conference, most notably Ronald Reagan and the other business leaders that we think are responsible for dislocating workers in the first place."

Inside, outside

Post-Gazette 4/7/83

Soaked protesters wait in vain for president's car

The mood fluctuated from hatred — of anybody who had anything to do with their plight — to anger, frustration and, finally, resignation.

They were the outsiders who stood in a cold, steady rain for four hours at the Pittsburgh Hilton waiting to see their president.

Inside the hotel, guests wore finely pressed suits.

Outside, the clothes and hair of the demonstrators were drenched. The ink from their hand-painted signs washed off in the rain.

They had come to vent their anger at President Reagan, to demand help for the unemployed. That was the dominant theme, although others were keen to express their views on El Salvador and cruise missiles.

(This story was written by Post-Gazette staff writer Jan Ackerman based on her reporting and that of staff writers Phillip Davis, Michael Reilly and Jim Gallagher.)

But they never saw Reagan.

"He'd talk about the unemployed, but not to them," said 71-year-old Leonard Weiser, a retired steel worker from Canonsburg. "I can't say I blame him. If I were him, I wouldn't face this mob."

"He didn't give a damn about us then [1980] and he doesn't give a damn about us now," Pat Bujarski, a member of Association of Community Organizations for Reform Now, told a rally on in front of the U. S. Steel building on Grant Street that preceded the major rally at Point State Park.

The protesters carried signs that told their stories: "We want jobs, not cheese." "Put Reagan on $50 plus cheese."

Some were seasoned veterans of protests who have demonstrated for the peace movement or for a nuclear freeze.

But the vast majority of the crowd con-

(Continued on Page 4, Column 2)

OVER

t's Visit

Pgh. Press

Rainy Wait Was In Vain For Crowd Outside Hilton

By DON HOPEY

ABOUT 4,500 PEOPLE who wanted to see President Reagan, and who wanted him to see them, stood in the rain, in vain, outside the Pittsburgh Hilton.

Pittsburgh's presidential gawkers squeezed onto curbs and corners overpopulated by the area's unemployed for a wait that began as early as 9 a.m. for some, but the guest of honor never showed his face outside the Hilton.

Yesterday, as the sky fell down around the ankles of those lining Commonwealth Place and Liberty Avenue five and six deep, Reagan ran an end-around that would have made the Gipper proud.

Police and Secret Service agents set up barricades around the Commonwealth Place and Liberty Avenue entrances of the Downtown hotel, diverting the attention of the protesters and president-watchers, while Reagan slipped in and out the back door of the hotel through an underground garage off Fort Duquesne Boulevard, virtually unnoticed.

On the Liberty Avenue side, the angry crowd chanted obscenities at police and Secret Service agents guarding staff cars, and called for Reagan to come down and meet the "real people."

At least one scuffle between police and two or three protesters broke out briefly. At least two people were taken into custody and released later without being charged.

Others in the crowd climbed into trees and on top of subway construction fences for a glimpse of the president while he was inside the hotel.

The barking of police dogs, used to clear the way for the staff car motorcade, was drowned out by the crowd's repeated chanting.

"Reagan, Reagan, he's no good; send him back to Hollywood," they shouted.

"Out the door in '84."

Had Reagan used the front door to enter the hotel for his speech to the conference arranged by the National Alliance of Business, he would have been showered not only with the angry chants and boos of unemployed steelworkers assembled in Point State Park, but perhaps with jellybeans, too.

"I've got some jellybeans here and I'm going to toss them at him," said Catherine Perla of Crafton Heights, as she stood on the curb near the hotel's front entrance and patted a bulging purse. "They're my lunch, but I'd gladly give them up for him."

Ms. Perla, unemployed and on extended benefits, said Reagan's jobs bill offers limited relief for the unemployed workers, and none for unemployed women.

"The jobs bill and jobs retraining are drops in the bucket," she said. "Reagan has to do something for women, too. He has no retraining plan for us. We've got to start working together or we're going down the drain."

Standing back from the curb on Commonwealth Place, but also near the hotel entrance, 74-year-old Michael Bogdon of East Carnegie said he was lucky to be retired.

"I'm worried about these youngsters who don't have jobs," said Bogdon, who began his vigil at 9:30 a.m. "What are they going to have when they grow up?

"If I could see the president, I'd tell him to start putting people back to work," Bogdon said, "but personally, I don't see things getting any better."

Joseph Reese, an unemployed television cable worker from Burgettstown, crowded close to the hotel — holding neither an umbrella nor a protest sign but, instead, his 4-year-old daughter, Caralee.

Caralee said she didn't mind "getting wet just a little bit" to see if the president is as cute in person as he is on the television set at home.

"She's excited," Reese said. "All she's been talking about is seeing him. I had to bring her down."

Barbara Murawski, a member of the People Concerned for the Unborn Child, an anti-abortion group, was in a curb position in front of the Hilton at 11 a.m., to welcome the president.

"I love President Reagan," Mrs. Murawski said shortly after David McAlpine, an unemployed steelworker from Baldwin, ripped apart a banner the group had unfurled to welcome the president. "Reagan is the best thing that ever happened to the unborn child."

Richard Geralds, the operations director for Warren General Hospital, in Warren, drove 100 miles for a meeting in Pittsburgh yesterday, and was surprised by the president's visit.

"I didn't realize that Reagan was coming until I got here, but once I was here I had to see what this was all about," Geralds said. "I haven't been part of a crowd like this since my college protest days when I went to Washington to march against Nixon.

"It's interesting because I've switched allegiances, had a true reversal," he continued. "I used to say 'why don't you do something for us,' but now I realize that things get done because individuals do them. I have a lot of trouble with what these people are screaming about."

Robert Light, a commercial printing salesman, waited for over two hours to see Reagan and was one of the few who saw Reagan's limousine exit the underground parking lot onto Fort Duquesne Boulevard.

"I voted for him and I think he's done a good job so far," Light said. "The steelworkers have a legitimate beef, but Reagan's been in a tough situation. They're trying to make their feelings known this way, but I wonder how many will vote in the next election."

4/7/83
Post Gazette

Darrell Sapp/Post-Gazette

Crowd of protesters looks large from inside the Hilton Hotel . . .

Reagan misses protesters

(Continued from Page 1)

sisted of unemployed steel workers who had disdained Vietnam War protests, but who now found themselves waving signs and shouting obscenities against Reagan, the man they say has left them down.

"Reagan, Reagan, he's no good; send him back to Hollywood," they chanted.

"This guy is no Roosevelt," said Dominec DelTurco, 76, of Ambridge, retired from the United Steelworkers of America, in which he had helped organize labor in the 1930s and 1940s. "Roosevelt was a compassionate man."

"I hear he was using this to get an idea about what running in 1984 will be like," said Charles Derr, a 49-year-old Pittsburgh resident who is on disability. "He didn't come out, so he must have got the idea."

The rain that started as a drizzle before 10 o'clock was coming down heavily by 11:30 a.m. It rained steadily for more than an hour, soaking the crowd.

"The bastard ain't worth standing in the rain for," said Ron Victor, a member of United Steelworkers Local 7097, Neville Island, as he stood by the Hilton.

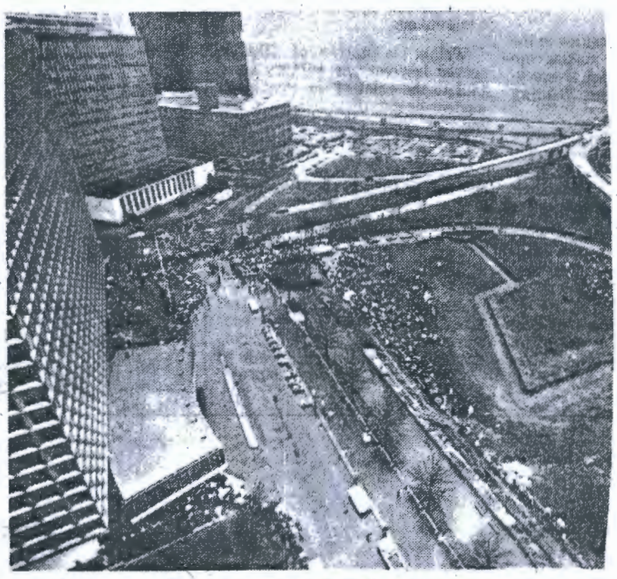
Reagan's limousine was whisked into the Hilton through a loading dock off Fort Pitt Boulevard just after 1:15 p.m., far away from most of the angry demonstrators, who began coming to Point State Park at the front of the Hilton at about 11 a.m.

The crowd pushed closer to the hotel after Reagan was inside. Protesters hung from trees and from scaffolding and construction trailers from the subway construction, trying to get a glimpse of the president. The lunchtime crowd of Downtown workers mingled with the protesters, standing under eaves of buildings.

Police blocked off Stanwix Street and kept the crowd at bay with K-9 dogs. By then, the mood had turned ugly and the chanting more intense.

"Reagan's a jerk, put us back to work," protesters shouted, raising their middle fingers in insult and shaking their fists. They mistook the press and White House staff motorcade for Reagan's when it first pulled up, and reacted with a long, sustained and very loud boo. They chanted insults when the motorcade drove away, still insisting, "We want Reagan."

Contacted later yesterday in Washington, White House spokesman Larry Speakes said the president may have seen about 75 demonstrators and heard some catcalls. Asked whether the president had any reaction, Speakes said, "His coming here is in reaction to them."



. . . But is clearly much less than 10,000 predicted by protest organizers.

Yesterday's rally of unemployed workers protesting Reagan's visit to Pittsburgh didn't reach the numbers promised by its organizers, USW Districts 15 and 20 and the Mon Valley Unemployed Committee.

One official had predicted a crowd of 10,000. But Assistant Police Superintendent Mayer DeRoy estimated yesterday's crowd at 4,500.

The size of the crowd was hard to gauge because protesters stood in clusters around the park and never really got together in one place. Both DeRoy and Superintendent Robert Coll said it was the most hostile crowd that has appeared at a presidential visit in their experience as Pittsburgh policemen.

"There's been hostility [before], but not this kind of hostility," said Coll shortly after the motorcade left the hotel.

DeRoy said there were three arrests of disorderly demonstrators. All three were placed in police wagons, then released without charges when they calmed down.

There was no violence, though the crowd grew more angry after learning that the president had been slipped into the hotel. The only near-incident was when police drove a phalanx of motorcycles through the crowd to meet the parked motorcade.

Earlier in the morning, an angry unemployed steel worker, David McAlpine of Baldwin, ripped down a 6-foot wide banner saying "Welcome Mr. President" brought to the rally by the group People Concerned about the Unborn Child.

Marcy Meenan of Beechview, who was holding the sign, said her group is sympathetic to the plight of steel workers but supports the president's views on the abortion issue.

"It is our American right to be here," she said.

Police used dogs to separate the crowd for the motorcycles, and police engaged with brief shoving matches with a few protesters.

The crowd was angry that Reagan did not hear their complaints personally. But Coll said the decision to bring Reagan in through the back door was made a week ago.

It had nothing to do with the demonstration, he said. Police prefer this because there is less chance of a sniper getting a shot at the president.

The rally groups had formed early in outlying towns as far away as Youngstown and Steubenville. Steel workers gathered at their local union halls to board buses coming into the city. Some of the buses dropped off protesters at the Hilton, while others parked at Three Rivers Stadium and let the protesters walk across the Fort Duquesne Bridge.

Unemployed steel worker William Mazza, 55, laid off after 33 years at U.S. Steel's National plant in McKeesport, said he used to think — especially during the Vietnam War — that protesters were radicals. But Mazza considered yesterday's protest different from the Vietnam movement.

"This is the movement of the worker," said Mazza, as he waited to board a bus at USW Local 1408 in McKeesport. "This rally goes back in my mind to my father's time, when they were organizing the unions."

"I thought they were all hippies 'til recently," said John Nordine, standing with friends in front of the Hilton Hotel. "But being out of work over a year changes how you see things."

The Mon Valley committee members started their protest on the steps of the U.S. Steel building, where about 400 damp people stood by the columns to get out of the rain and to listen to speakers address every subject from Reagan to the Ku Klux Klan.

They marched from the building to Point State Park, chanting in unison, "Ronnie, Ronnie, he's no good; Send him back to Hollywood."

Stark file

NATIONAL COMMITTEE FOR ADOPTION
SUITE 326
1346 CONNECTICUT AVENUE, N.W.
WASHINGTON, D. C. 20036

202 - 463-7559

January 20, 1983

Maiselle Shortley
310 North Pitt
Alexandria VA 22314

Dear Maiselle:

It was very good talking with you about adoption. I share your frustration with those agencies that, even if they cannot work with parents, act in ways that are less than "charitable."

As promised, I'm enclosing several copies of our newsletter promoting the adoption option for teens -- and the HOTLINE! Please share them, encourage people to copy the back page and put it up everywhere teens may congregate.

I got the sense, during our conversation, that you and your husband are interested in exploring adoption of another child. If you are, you might want to read SUCCESSFUL ADOPTION for some hints that may be helpful. It's available in many libraries and we also distribute it. An order form is enclosed, for your convenience.

I also share your frustration with the situation of young women not going to agencies -- and therefore of agencies not being able to place babies. This is part of a problem in the whole national picture that needs addressing and one which, if we are successful, we will begin to turn around in the years ahead. Unfortunately, the situation deteriorated over 20 years and we will have a 20-year struggle to try and right things. Meanwhile, we've got many forces and most of the media against us -- they think a young woman is "heartless" if she plans adoption. We also have financial barriers to reasonable fees to make the system work, opposition from State-level bureaucrats, and lots of other problems.

I hope to see you tomorrow and chat briefly prior to the meeting. Please let me hear from you.

Sincerely,

Bill

William L. Pierce, Ph.D.
President

P.S. If possible, can you send me a list of invitees after the meeting's over? Of course, depending on the protocol....

file
Right to
Life

TABLE OF CONTENTS

TAB 1

TALKING POINTS ON PROPOSED INFANT DOE REGULATION

Background

-- On April 30, 1982, following the death of a newborn infant with Down's syndrome in Bloomington, Indiana, from whom nourishment and surgery to correct a detached esophagus was withheld, President Reagan instructed the Secretary of HHS to remind federally assisted health care providers that discrimination on the basis of handicap in the provision of medical care to handicapped infants was in violation of Section 504 of the Rehabilitation Act of 1973.

-- On May 18, 1982, HHS issued a notice to all hospitals which receive federal financial assistance under the Medicare and Medicaid programs reminding them that under section 504, it is unlawful to discriminatorily withhold medically indicated treatment from handicapped infants.

-- On March 7, 1983, HHS issued an interim final rule requiring hospitals which receive federal financial assistance to post notices in the hospital advising of the provision of section 504 in connection with treatment of handicapped infants and of the availability of a toll-free telephone hotline established by HHS to receive reports of suspected violation of the law.

-- On April 14, 1983, Judge Gerhard Gesell of the U.S. District Court for the District of Columbia declared the March 7 interim final rule invalid on the grounds that HHS improperly failed to provide for public comment prior to the effective date of the rule and to establish a sufficient administrative record to show the rule was not "arbitrary and capricious." The court's decision did not affect the May 18, 1982 notice to health care providers or the operation of the toll-free hotline. HHS filed a notice of appeal of the court's decision.

Provisions of the Proposed Regulation

-- The new rule is being issued as a notice of proposed rulemaking, providing for a 60-day comment period. Following the comment period, a final rule will be issued, to be effective not less than 30 days thereafter.

-- The notice of proposed rulemaking is accompained by an appendix and extensive preamble clarifying that in applying section 504 to issues concerning health care for handicapped infants, HHS would not interfere with legitimate medical judgments. For example, section 504 does not require futile medical treatment for infants whose impairments are so severe that death is imminent and unavoidable.

-- In order to develop a more extensive administrative record, the notice of proposed rulemaking also solicits public comment on the full range of issues relating to health care for handicapped infants and the applicability of section 504 in these cases.

-- Like the March 7 interim final rule, the proposed rule would require that hospitals which receive federal financial assistance to post notices advising of the protections of section 504 and of the availability of the toll-free hotline to report suspected violations. The proposed rule revises this provision, however, to require only that the notice be posted at the nurses' stations of hospital wards and units where infants receive treatment, rather than in locations where it would also be conspicuous to the public.

-- In recognition of the role of parents in decision making regarding their children and of State authority in assuring that parental responsibilities are not exercised improperly, the proposed rule would increase the involvement of State child protective services agencies by: (a) requiring that the telephone number of the child protective services agency be included on the notice, along with the HHS hotline number; and (b) requiring that State child protective services agencies maintain procedures and methods of administration to assure that child protective services are provided to handicapped infants in a nondiscriminatory manner.

-- Like the March 7 interim final rule, the proposed rule would, in view of the life-and-death emergency nature of "Infant Doe" cases, slightly revise investigation and enforcement procedures to: (a) waive the normal 10-day waiting period before suspected violations are referred to the Department of Justice for legal action to obtain compliance; and (b) permit access to pertinent records on a 24-hour basis, rather than only during normal business hours.

TAB 2

4/30

THE WHITE HOUSE

WASHINGTON

MEMORANDUM FOR THE ATTORNEY GENERAL
THE SECRETARY OF HEALTH AND HUMAN SERVICES

SUBJECT: Enforcement of Federal Laws Prohibiting Discrimination Against the Handicapped

Following the recent death of a handicapped newborn child in Indiana, many have raised the question whether Federal laws protecting the rights of handicapped citizens are being adequately enforced.

Therefore, I am instructing Secretary Schweiker to notify health care providers of the applicability of section 504 of the Rehabilitation Act of 1973 to the treatment of handicapped patients. That law forbids recipients of Federal funds from withholding from handicapped citizens, simply because they are handicapped, any benefit or service that would ordinarily be provided to persons without handicaps. Regulations under this law specifically prohibit hospitals and other providers of health services receiving Federal assistance from discriminating against the handicapped.

I am also instructing the Attorney General to report to me on the possible application of Federal constitutional and statutory remedies in appropriate circumstances to prevent the withholding from the handicapped of potentially life-saving treatment that would be given as a matter of course to those who are not handicapped.

Our Nation's commitment to equal protection of the law will have little meaning if we deny such protection to those who have not been blessed with the same physical or mental gifts we too often take for granted. I support Federal laws prohibiting discrimination against the handicapped, and remain determined that such laws will be vigorously enforced.

TAB 3

medicare
Part A Intermediary Letter

Department of Health
and Human Services

Health Care Financing
Administration

Transmittal No. 82-11

Date May 1982

SUBJECT: Implementation of Section 504 (P.L. 93-112) to Assure Non-Discrimination Against Handicapped Persons

Please reprint and distribute immediately to all hospitals the attached message prepared by the Office of Civil Rights concerning implementation of section 504 (P.L. 93-112).

We recognize that recipients of Federal financial assistance may not have full control over the treatment of handicapped patients when, for instance, parental consent has been refused. Nevertheless, a recipient may not aid or perpetuate discrimination by significantly assisting the discriminatory actions of another person or organization. 45 C.F.R. 84.4(b)(1)(v). Recipients must accordingly insure that they do not violate section 504 by facilitating discriminatory conduct.

In fulfilling its responsibilities, a Federally assisted health care provider should review its conduct in the following areas to insure that it is not engaging in or facilitating discriminatory practices:

- Counseling of parents should not discriminate by encouraging parents to make decisions which, if made by the health care provider, would be discriminatory under section 504.

- Health care providers should not aid a decision by the infant's parents or guardian to withhold treatment or nourishment discriminatorily by allowing the infant to remain in the institution.

- Health care providers are responsible for the conduct of physicians with respect to cases administered through their facilities.

The failure of a recipient of Federal financial assistance to comply with the requirements of section 504 subjects that recipient to possible termination of Federal assistance. Moreover, section 504 does not limit the continued enforcement of State laws prohibiting the neglect of children, requiring medical treatment, or imposing similar responsibilities.

Betty Lou Dotson

Betty Lou Dotson
Director, Office for Civil Rights

DEPARTMENT OF HEALTH & HUMAN SERVICES

Office of the Secretary

Washington, D.C. 20201

May 18, 1982

NOTICE TO HEALTH CARE PROVIDERS

SUBJECT: Discriminating Against the Handicapped by Withholding Treatment or Nourishment

There has recently been heightened public concern about the adequacy of medical treatment of newborn infants with birth defects. Reports suggest that operable defects have sometimes not been treated, and instead infants have been allowed to die, because of the existence of a concurrent handicap, such as Down's syndrome.

This notice is intended to remind affected parties of the applicability of section 504 of the Rehabilitation Act of 1973 (29 U.S.C. 794). Section 504 provides that "No otherwise qualified handicapped individual...shall, solely by reason of his handicap, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance...." Implementing regulations issued by the Department of Health and Human Services make clear that this statutory prohibition applies in the provision of health services (45 C.F.R. 84.52) and that conditions such as Down's syndrome are handicaps within the meaning of section 504 (45 C.F.R. 84.3(j)).

Under section 504 it is unlawful for a recipient of Federal financial assistance to withhold from a handicapped infant nutritional sustenance or medical or surgical treatment required to correct a life-threatening condition, if:

(1) the withholding is based on the fact that the infant is handicapped; and

(2) the handicap does not render the treatment or nutritional sustenance medically contraindicated.

For example, a recipient may not lawfully decline to treat an operable life-threatening condition in an infant, or refrain from feeding the infant, simply because the infant is believed to be mentally retarded.

TAB 4

Federal Register

Monday
March 7, 1983

Part II

Department of Health and Human Services

Office of the Secretary

Nondiscrimination on the Basis of Handicap

DEPARTMENT OF HEALTH AND HUMAN SERVICES

Office of the Secretary

45 CFR Part 84

Nondiscrimination on the Basis of Handicap

AGENCY: Office of the Secretary, HHS.

ACTION: Interim final rule.

SUMMARY: The interim final rule modifies existing regulations to meet the exigent needs that can arise when a handicapped infant is discriminatorily denied food or other medical care. Three current regulatory provisions are modified to allow timely reporting of violations, expeditious investigation, and immediate enforcement action when necessary to protect a handicapped infant whose life is endangered by discrimination in a program or activity receiving federal financial assistance.

Recipients that provide health care to infants will be required to post a conspicuous notice in locations that provide such care. The notice will describe the protections under federal law against discrimination toward the handicapped, and will provide a contact point in the Department of HHS for reporting violations immediately by telephone.

Notice and complaint procedures have been effective instruments for deterrence and enforcement in a variety of civil rights contexts. The Secretary believes that the interim final rule provides the best means to ensure that violations can be reported in time to save the lives of handicapped children who are denied food or are otherwise imperiled by discrimination in the provision of health care by federally assisted programs or activities.

The procedures to be followed for investigation of complaints are outlined in the supplementary information below. The Secretary intends to rely heavily on the voluntary cooperation of State and local agencies, which are closest to the scene of violations, and which have traditionally played the key role in the investigation of complaints of child abuse and neglect. This will not exclude, of course, a vigorous federal role in enforcing the federal civil rights that are at issue.

The Secretary invites comments on all aspects of the interim final rule. Aspects on which comment is particularly invited are set forth in the supplementary information.

DATES: The interim final rule becomes effective March 22, 1983.

Comments should be submitted by May 6, 1983.

ADDRESSES: Comments should be submitted in writing to the Director, Office for Civil Rights, Department of Health and Human Services, 330 Independence Avenue, S.W., Room 5400, Washington, D.C. 20201, or delivered to the above address between 9:00 a.m. and 5:30 p.m. on regular business days. Comments received may be inspected during these same hours by making arrangements with the contact person shown below.

FOR FURTHER INFORMATION CONTACT: Susan Shalhoub at (202) 245–6585, Office for Civil Rights, Department of Health and Human Services, 330 Independence Avenue, S.W., Room 5514, Washington, D.C. 20201.

SUPPLEMENTARY INFORMATION: The President's directive of April 30, 1982, and the HHS Office for Civil Rights "Notice to Health Care Providers" of May 18, 1982, reminded recipients of federal financial assistance of the applicability of Section 504 of the Rehabilitation Act of 1973. Section 504 provides: "No otherwise qualified handicapped individual . . . shall, solely by reason of his handicap, be excluded from participation in, be denied the benfits of, or be subjected to discrimination under any program or activity receiving federal financial assistance."

The Notice to Health Care Providers explained what is already clear from the language of Section 504 and the implementing regulations (45 CFR Part 84): The discriminatory failure of a federally assisted health care provider to feed a handicapped infant, or to provide medical treatment essential to correct a life-threatening condition, can constitute a violation of Section 504.

This interim final rule does not in any way change the substantive obligations of health care providers previously set forth in the statutory language of Section 504, in the implementing regulations, and in the Notice to Health Care Providers. The interim final rule sets forth procedural specifications designed: (1) To specify a notice and complaint procedure, within the context of the existing regulations, and (2) to modify existing regulations to recognize the exigent circumstances that may exist when a handicapped infant is denied food or other necessary medical care.

The interim final rule affects the following portions of existing regulations:

1. *45 CFR 80.6(d)*, as referenced by 45 CFR 84.61, which requires recipients to make available such information, in such a manner, as the Department finds necessary to apprise appropriate persons of the protections afforded under Section 504. The interim final rule specifies the type of information and manner of posting that is necessary to bring the protections of Section 504 for handicapped infants to the attention of those persons within the recipient program or activity who are most likely to have knowledge of possible violations as they occur.

2. *45 CFR 80.8*, as referenced by 45 CFR 84.61, which sets forth procedures for the Secretary to effect compliance with Section 504, including referrals to the Department of Justice for the initiation of appropriate legal proceedings. The existing regulations require a 10-day waiting period from the time the Secretary notifies a recipient of its failure to comply to the time the Secretary makes a referral to the Department of Justice or takes other legal actions to effect compliance. When a handicapped infant is being denied food or other necessary medical care, however, more expeditious action may be required. New § 84.61(c) creates a narrow exception to the 10-day waiting period when, in the judgment of the responsible Department official, immediate remedial action is necessary to protect the life or health of a handicapped individual.

3. *45 CFR 80.6(c)*, as referenced by 45 CFR 84.61, which requires each recipient to permit access by Department officials to facilities and information pertinent to ascertaining compliance with Section 504, during normal business hours. Allegations of denial of food or other necessary medical care to handicapped infants may require an immediate effort to ascertain compliance. The interim final rule provides that access to records and facilities of recipients shall not be limited to normal business hours when, in the judgment of the responsible Department official, immediate access is necessary to protect the life or health of a handicapped individual.

The purpose of the interim final rule is to acquire timely information concerning violations of Section 504 that are directed against handicapped infants, and to *save the life of the infant*. The Secretary believes that those having knowledge of violations of Section 504 against handicapped infants do not now have adequate opportunity to give immediate notice to federal authorities. A telephone complaint procedure can provide information to federal authorities in time to save the life of a handicapped infant who is being discriminatorily denied nutrition in a federally assisted program or activity.

Events of the past several years suggest that handicapped infants have died from denial of food in federally assisted programs. The full extent of discriminatory and life-threatening practices toward handicapped infants is not yet known, but the Secretary believes that for even a single infant to die due to lack of an adequate notice and complaint procedure is unacceptable.

For quick and effective response to complaints, the Secretary counts not only the enforcement resources of the federal government, but also on the assistance of state child protective agencies, which can respond quickly and effectively to referrals from the Federal government, and which are often closest to the scene for speedy investigation of life-threatening child abuse and neglect. The Secretary intends to contact state child protective agencies whenever a complaint is received that falls within the definition of child abuse or neglect, in order to give States an opportunity to make their own investigation and to take appropriate action.

The Secretary expects that States will follow their customary procedures for investigating allegations of child abuse and neglect that involve an imminent danger to life. State agencies that receive federal financial assistance are under the same obligation as other recipients not to provide a qualified handicapped person with benefits or services that are less effective than those provided to others.

For those complaints that are expeditiously and effectively investigated and pursued by State agencies, the Secretary anticipates that additional federal efforts will often be unnecessary. The Secretary will closely monitor all investigation and enforcement activity taken pursuant to complaints. The Secretary will make available to State agencies any information and assistance that is helpful and appropriate. For those cases where direct federal action appears helpful, the Secretary will have at his disposal the usual means of federal civil rights enforcement. The interim final rule makes it possible for the Secretary to conduct immediate investigations and to make immediate referrals to the Department of Justice for such legal action as may be necessary to save the life of a handicapped child who is subjected to discrimination by a recipient.

Federal enforcement action can also be taken against any recipient that intimidates or retaliates against any person who provides information concerning possible violations of Section 504. 45 CFR 80.7(e), as referenced by 45 CFR 84.61, prohibites intimidatory or retaliatory acts by recipients against individuals who make complaints or assist in investigations concerning possible violations of Section 504. This provision fully protects individuals who make complaints or assist in investigations concerning possible withholding of food or other necessary medical care from handicapped infants.

Comments solicited. The Secretary seeks public comment on all aspects of the interim final rule. Comments will be considered and modifications made to the rule, as appropriate, following the comment period.

The Secretary also solicits comments on the advisability of requiring (1) that recipients providing health care services to infants perform a self-evaluation, pursuant to 45 CFR 84.6(c)(1), with respect to their policies and practices concerning services to handicapped infants; and (2) that such recipients identify for parents of handicapped children those public and private agencies in the geographical vicinity that provide services to handicapped infants.

Regulatory impact analysis. This rule has been reviewed under Executive Order 12291. It is not a major rule and thus does not require a regulatory impact analysis.

Regulatory flexibility analysis. The Regulatory Flexibility Act (Pub. L. 96-354) requires the federal government to anticipate and reduce the impact of rules and paperwork requirements on small businesses and other small entities. This rule has no significant effect on small entities. Therefore, a regulatory flexibility analysis is not required.

Paperwork Reduction Act. This rule contains no information collection requirements subject to the Paperwork Reduction Act of 1980 (Pub. L. 96-511).

Public participation in rulemaking. With reference to the Secretary's Statement of Policy, dated January 28, 1971, concerning public participation in rulemaking (printed at 36 FR 2532; Feb. 5, 1971), the Secretary finds that this interim final rule is exempt from the requirements of 5 U.S.C. 553. Under 45 CFR 80.6(d) and 84.61, the Secretary is already authorized to specify the manner in which recipients make available information concerning federal legal protections against discrimination toward the handicapped. The exception to the 10-day waiting period of 45 CFR 80.8(d)(3) and the exception to 45 CFR 80.6(c) to allow access outside normal business hours are minor technical changes and are necessary to meet emergency situations. All modifications made by the interim final rule are necessary to protect life from imminent harm. Any delay would leave lives at risk. Immediate publication and implementation of this rule will not cause undue burden to any party. The Secretary therefore finds it necessary to publish this rule as an interim final rule taking effect less than 30 days following publication. The Secretary deems 15 days to be the minimum in which the necessary apparatus can be in place to receive and respond to telephone complaints. The interim final rule is therefore made effective March 22, 1983.

List of Subjects in 45 CFR Part 84

Civil rights, Education of handicapped, Handicapped.

Approved: March 2, 1983.

Thomas R. Donnelly, Jr.,
Acting Secretary.

PART 84—[AMENDED]

Interim Final Rule

45 CFR 84.61 is amended by designating the existing provision as paragraph (a) and by adding paragraphs (b), (c), and (d) to read as follows:

§ 84.61 [Amended]

* * * * *

(b) Pursuant to 45 CFR 80.6(d), each recipient that provides covered health care services to infants shall post and keep posted in a conspicuous place in each delivery ward, each maternity ward, each pediatric ward, and each nursery, including each intensive care nursery, the following notice:

DISCRIMINATORY FAILURE TO FEED AND CARE FOR HANDICAPPED INFANTS IN THIS FACILITY IS PROHIBITED BY FEDERAL LAW

Section 504 of the Rehabilitation Act of 1973 states that no otherwise qualified handicapped individual shall, solely by reason of handicap, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving federal financial assistance.

Any person having knowledge that a handicapped infant is being discriminatorily denied food or customary medical care should immediately contact:

Handicapped Infant Hotline
U.S. Department of Health and Human Services
Washington, D.C. 20201
Phone 800- ———— (Available 24 hours a day)
or
Your State Child Protective Agency

Federal law prohibits retaliation or intimidation against any person who provides information about possible violations of the Rehabilitation Act of 1973.

Identity of callers will be held confidential.

Failure to feed and care for infants may also violate the criminal and civil laws of your State.

(1) Recipients may add to the notice, in type face or handwriting, under the words "Your State Child Protective Agency," the identification of an appropriate State agency, with address and telephone number. No other alterations shall be made to such notice.

(2) Copies of such notice may be obtained on request from the Department of Health and Human Services.

(3) The required notice shall be posted within five days after the recipient is informed by the Department of the applicable toll-free national telephone number.

(c) Notwithstanding the provisions of paragraph (a), the requirement of 45 CFR 80.8(d)(3) shall not apply when, in the judgment of the responsible Department official, immediate remedial action is necessary to protect the life or health of a handicapped individual.

(d) Notwithstanding the provisions of paragraph (a), access to pertinent records and facilities of a recipient pursuant to 45 CFR 80.6(c) shall not be limited to normal business hours when, in the judgment of the responsible Department official, immediate access is necessary to protect the life or health of a handicapped individual.

[FR Doc. 83-5781 Filed 3-4-83; 9:42 am]
BILLING CODE 4150-04-M

TAB 5

IN THE UNITED STATES DISTRICT COURT

FOR THE DISTRICT OF COLUMBIA

AMERICAN ACADEMY OF PEDIATRICS, NATIONAL ASSOCIATION OF CHILDREN's HOSPITALS AND RELATED INSTITUTIONS, CHILDREN's HOSPITAL NATIONAL MEDICAL CENTER, Plaintiffs,	)	
v.	)	Civil Action No. 83-0774
MARGARET M. HECKLER, Secretary, Department of Health and Human Services, Defendant.	)	

MEMORANDUM

This case involves the validity of an interim final regulation published by the defendant Secretary on March 7, 1983, without benefit of public comment, concerning the care and treatment of newborn infants in some 6,400 hospitals receiving federal funds. Plaintiffs contend that the regulation is arbitrary and capricious, that no justification existed for dispensing with public comment as required by the Administrative Procedure Act (APA), that the Secretary lacked statutory authority to act and that the regulation intrudes without justification into family-physician and other confidential relationships protected by the Constitution. A temporary restraining order was denied. These difficult issues are now before the Court after a full hearing on the merits.[1] The following constitute the Court's findings of fact and conclusions of law.

Background

This case touches upon one of the most difficult and sensitive medical and ethical problems facing our society -- the question of what sort of life-sustaining medical treatment, if any, should be utilized to preserve the lives of severely mentally or physically defective newborn infants. Sometimes surgery or other life-sustaining treatment allows an otherwise seriously ill infant to attain complete health and develop normally. Frequently, however, correction of a life-threatening physical defect or use of heroic life-sustaining measures preserves the life of an infant who continues nevertheless to suffer from mental or physical defects so great as seriously to impair the infant's expected quality of life and chances for an independent existence.[2/]

Some physicians apply all available life-sustaining techniques in these cases, even where the infant's death due to a severe defect is certain. However, traditionally many attending physicians confronted with a severely defective newborn may, after medical consultation and discussion with family members, agree not to undertake corrective surgery or other life-sustaining measures. The decision to forgo life-preserving measures in these desperate cases is complex and may involve a number of potentially conflicting ethical concerns. In some instances parents and physicians deciding upon a course of medical treatment may, among other factors, consider the risks of treatment; the

quality of life the infant will enjoy if it survives; the utility of further life-sustaining measures in the face of a prognosis that certain death will occur in weeks or months; and the impact of a severely mentally or physically defective child upon the parents' marriage, other siblings, and the family's financial resources.

Traditionally, the difficult decision of when to withhold life-sustaining treatment of a defective newborn has been one made within the privacy of the physician-patient relationship, without interference by state or federal authorities. Physicians, after counseling parents on options affecting prognosis and treatment, frequently give great deference to the wishes of the parents who are considered guardians of the best interests of the child. There may be a joint decision that life-sustaining measures should be withheld. However, in other situations physicians may proceed contrary to parental instructions and perhaps even seek court intervention on the child's behalf. There is evidence that the medical judgments being reached are not always free of error, particularly in borderline cases and where parental decisions may reflect primarily economic and familial considerations which some find wholly irrelevant.

The problem of serious illness or birth defect in newborn infants is, of course, not a new one. But dramatic advances in neonatal care have made it now possible to sustain some form of life in many infants who decades or

even years ago usually died shortly after birth. Moreover, recent publicity surrounding certain cases where parents or physicians have determined not to undertake life-sustaining treatment of defective but possibly salvageable newborns has focused public debate on this delicate and sensitive issue.

Not surprisingly there is heated controversy as to how best to determine the appropriate course of medical care for these infants. These concerns appear to have been sparked by the "Baby Doe" case in Bloomington, Indiana. Baby Doe was born April 9, 1982, afflicted with Down's syndrome (mongolism) and a surgically correctable blockage of his digestive tract which precluded normal feeding. His parents refused to consent to surgery and the hospital turned to the state courts for guidance. Despite appointment of a guardian ad litem and several attempts at appeal, no judicial intervention occurred and the infant died six days later.

This case was widely publicized and evoked much public discussion. President Reagan sent a memorandum to the Attorney General and the then-Secretary of Health and Human Services (HHS) dated April 30, 1982, citing the "Baby Doe" case and noting that federal law prohibits discrimination against the handicapped. In response, the Secretary issued a May 18, 1982 "notice" to health care providers "to remind affected parties of the applicability of section 504 of the Rehabilitation Act of 1973." 47 Fed. Reg. 26027 (June 16,

1982). That notice stated that section 504 made it unlawful for hospitals receiving federal financial assistance to withhold nutrition or medical or surgical treatment from handicapped infants if required to correct a life-threatening condition. The notice went on to recognize that recipients of federal financial assistance do not have complete control over treatment, especially where parental wishes are otherwise, but suggested that parental withholding of consent for treatment should not be aided by allowing the infant to remain in the receiving institution, and that failure to comply with section 504 subjected recipients "to possible termination of Federal assistance." Id.

Nearly a year later, on March 7, 1983, a newly-appointed Secretary published the regulation at issue in this case. 48 Fed. Reg. 9630.

The Challenged Regulation

The regulation issued by the Secretary is novel and far-reaching. It has provoked strong responses, both favorable and unfavorable, from those sections of the community concerned with the medical care of newborn infants or the civil rights of the handicapped.[3/] Like the notice of May 18, the regulation was also promulgated under section 504 of the Rehabilitation Act of 1973, which provides that

> [n]o otherwise qualified handicapped individual in the United States . . . shall, solely by reason of his handicap, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance. . . . 29 U.S.C. § 794.

Invoking this authority, the Secretary for the first time undertook actively to oversee the medical treatment of severely defective newborn infants and to safeguard their lives, acting as what counsel for defendant characterized "the protector of last resort."

The "interim final rule" became effective March 22, 1983. It requires hospitals and other medical institutions receiving federal financial assistance to post permanently "in a conspicuous place in each delivery ward, each maternity ward, each pediatric ward, and each nursery, including each intensive care nursery," the following sign:

DISCRIMINATORY FAILURE TO FEED
AND CARE FOR HANDICAPPED
INFANTS IN THIS FACILITY IS
PROHIBITED BY FEDERAL LAW

> Section 504 of the Rehabilitation Act of 1973 states that "no otherwise qualified handicapped individual shall, solely by reason of handicap, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving federal financial assistance."

Any person having knowledge that a handicapped infant is being discriminatorily denied food or customary medical care should immediately contact:

Handicapped Infant Hotline
U.S. Department of Health and Human Services
Washington, D. C. 20201
Phone 800-368-1019 (available 24 hours a day)
In the City of Washington, D. C. - 863-0100
(TTY capability)

or

Your State Child Protective Agency
[address and telephone number]

Federal law prohibits retaliation or intimidation against any person who provides information about possible violations of the Rehabilitation Act of 1973.

Identity of callers will be held confidential.

Failure to feed and care for infants may also violate the criminal and civil laws of your State.

Under the regulation a possible violation reported anonymously or otherwise via the "hotline" may be referred by the agency in turn to state child protective authorities or to the Department of Justice for civil rights enforcement. The regulation also authorizes immediate intervention by an HHS Office of Civil Rights investigation squad to protect the life or health of a handicapped infant. Institutions receiving federal financial assistance are required to give 24-hour access to hospital records and facilities during the investigation, and physicians, families and hospital staff are subject to immediate on-the-scene questioning while in the midst of providing newborn care and treatment.

The Regulation Fails To Satisfy The Requirements of the Administrative Procedure Act

The Administrative Procedure Act, 5 U.S.C. § 551, et seq., was designed to curb bureaucratic actions taken without consultation and notice to persons affected. Broad delegations of rulemaking authority from the Congress were

intended to be tempered by assuring a degree of due process for those to be governed by the rule. United States v. Morton Salt Co., 338 U.S. 632, 644 (1950). The greater the impact of the regulation upon established practices or the greater the number of people directly affected, the more the courts have insisted that the right of comment by those affected be preserved. American Federation of Government Employees v. Block, 655 F.2d 1153, 1156 (D.C. Cir. 1981). Thus the Act has been generally construed to curtail rulemaking without comment. Moreover, the Act requires that all regulations shall issue only after the rulemaker has considered relevant factors to prevent arbitrary and capricious decisionmaking and to assure rational consideration of the impact of the contemplated regulatory action. The instant regulation offends these established precepts to a remarkable extent.

When the Secretary issued the regulation, she had before her a videotape of an evocative series of investigative television broadcasts, entitled "Death In the Nursery," reviewing past publicized cases where medical treatment had been withheld from defective infants,[4/] as well as a series of newspaper accounts of the same and similar events and a MacNeil-Lehrer broadcast. Also available were articles in medical and academic journals, some surveys showing disparate medical practices, and reports of investigations undertaken by the HHS Office of

Civil Rights since the Baby Doe case which had failed to reveal any impropriety. In addition, Dr. C. Everett Koop, the Surgeon General and a distinguished pediatrician, gave the Secretary oral advice supporting the need for some sort of regulatory control in this area although he was not consulted as to this specific regulation.

Thus ground may have existed for undertaking a regulatory approach to the problem of how newborns should be treated in government-financed hospitals, if implementing authority could be found. Nevertheless, after full consideration of the entire record the Court finds that the interim final rule of March 7, 1983, is invalid as an arbitrary and capricious agency action which fails to meet the standard required under the Administrative Procedure Act, 5 U.S.C. § 706(2)(A).

The Court is well aware that agency rulemaking must be considered deferentially and that this Court is prohibited from substituting its own judgment for that of the agency if a rational basis exists for the agency's decision. Nevertheless, this Court may not, on the other hand, "rubber-stamp" challenged agency decisions and must inquire whether the agency's action was based on a consideration of the relevant factors. Citizens to Preserve Overton Park v. Volpe, 401 U.S. 402, 416 (1971); Wawszkiewicz v. Department of the Treasury, 670 F.2d 296, 301-304 (D.C. Cir. 1981). Lacking such consideration the regulation fails to

satisfy the test of rationality and cannot be sustained because it is arbitrary and capricious.

The record tendered in support of the Secretary's action here clearly establishes that many highly relevant factors central to any application of section 504 to medical care of newborn infants were not considered prior to promulgation of the challenged rule.

All matters considered by the Secretary are documented in Court Exhibit A. However, that record reflects no consideration whatsoever of the disruptive effects of a 24-hour, toll-free "hotline" upon ongoing treatment of newborns. As indicated, any anonymous tipster, for whatever personal motive, can trigger an investigation involving immediate inspection of hospital records and facilities and interviewing of involved families and medical personnel. In a desperate situation where medical decisions must be made on short notice by physicians, hospital personnel and often distraught parents, the sudden descent of "Baby Doe" squads on the scene, monopolizing physician and nurse time and making hospital charts and records unavailable during treatment, can hardly be presumed to produce higher quality care for the infant.[5/]

Nor are the interests of the child served by a regulation that contemplates forced removal of the child from a hospital if a parent refuses to allow medical care or the termination of any federal assistance to the hospital as

a whole, as suggested by the May 18 notice. No weighing of these factors is indicated in the record nor has any attempt been made to balance them against the malpractice and disciplinary risks that may be imposed upon physicians and hospitals caught between the requirements of the regulation and established legal and ethical guidelines.

It is clear that a primary purpose of the regulation is to require physicians treating newborns to take into account only wholly medical risk-benefit considerations and to prevent parents from having any influence upon decisions as to whether further medical treatment is desirable. The Secretary did not appear to give the slightest consideration to the advantages and disadvantages of relying on the wishes of the parents who, knowing the setting in which the child may be raised, in many ways are in the best position to evaluate the infant's best interests. Ignoring parental preferences again may increase the risk that parents will withdraw the infant from hospital care entirely, and the long-term interests of physically disabled newborns may be affected by thrusting the child into situations where economic, emotional and marital effects on the family as a whole are so adverse that the effort to preserve an unwanted child may require concurrent attention to procedures for adoption or other placement.

None of these sensitive considerations touching so intimately on the quality of the infant's expected life were

even tentatively noted. No attempt was made to address the issue of whether termination of painful, intrusive medical treatment might be appropriate where an infant's clear prognosis is death within days or months or to specify the level of appropriate care in such futile cases. Means of funding the extensive care mandated by the regulation and for allocating scarce medical resources between defective newborns and other newborns or other patients were also apparently not considered.

There can be no dispute as to the relevance of these issues under section 504 as the Secretary proposes it be applied. They are acknowledged and elaborated by informed briefs of amici and qualified experts on behalf of one or both parties.

Not only are these relevant factors not considered but there are other matters lacking in the rulemaking record. It contains no indication that the legal and constitutional considerations which should have guided the Secretary in her decisional process were reviewed. Neither the requirements of the Administrative Procedure Act nor questions as to the scope of section 504 were apparently noted. No alternative means of protecting handicapped infants were reviewed or considered although the Secretary was aware of the imminent release of the landmark report of the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavorial Research, which counsels different approaches

to the issue. Indeed, the record even fails to suggest a widespread denial of proper newborn care such as would justify the type of regulation selected.

As finder of fact, this Court is forced to conclude that haste and inexperience have resulted in agency action based on inadequate consideration. This is reinforced by the text of the rule itself. For example, the rule provides that it is a violation of federal law to deny a handicapped infant "customary medical care." Yet as all the evidence received by this Court from both parties has made clear, and as even the most cursory investigation by the Secretary would have revealed, there is no customary standard of care for the treatment of severely defective infants. The regulation thus purports to set up an enforcement mechanism without defining the violation, and is virtually without meaning beyond its intrinsic *in terrorem* effect.

Even if the regulation could withstand the requirements of 5 U.S.C. § 706(2)(a), it must be declared invalid due to the Secretary's failure to follow procedural requirements in its promulgation. It is undisputed that the rule was not issued in accordance with either the public notice or 30-day delay-of-effective date requirements of the APA. 5 U.S.C. § 553(b) and (d). The Secretary argues that the rule is either a "procedural" or "interpretative" rule not subject to the requirements of these provisions, or that waiver of these requirements is appropriate given the need "to protect

life from imminent harm." Neither of these arguments has merit.

As defendant's counsel acknowledged in argument, the regulation is intended, among other things, to change the course of medical decisionmaking in these cases by eliminating the parents' right to refuse to consent to life-sustaining treatment of their defective newborn.[6/] Moreover, the regulation provides for an intrusive on-premises enforcement mechanism that can be triggered by a simple anonymous call. Thus it clearly is more than a "clarification or explanation of an existing rule or statute" and affects substantive rights. Guardian Federal Savings and Loan Association v. FSLIC, 589 F.2d 658, 664 (D.C. Cir. 1978).

Nor has the Secretary demonstrated good cause why APA notice procedures should be waived. The "good cause" exceptions to sections 553(b) and (d) should be narrowly construed and only reluctantly countenanced, New Jersey v. Environmental Protection Agency, 626 F.2d 1038, 1045 (D.C. Cir. 1980). As already noted, this is particularly the case where the issues affect the general public and involve complex and controversial questions of ethics and public policy, as in this case. The Secretary argues that waiver is appropriate because "[a]ny delay would leave lives at risk." 48 Fed. Reg. 9631. Such an argument could as easily be used to justify immediate implementation of any sort of

health or safety regulation, no matter how small the risk for the population at large or how long-standing the problem. There is no indication in this case of any dramatic change in circumstances that would constitute an emergency justifying shunting off public participation in the rulemaking.[7/] American Federation, supra, at 1156.

The Application of Section 504

Because the Court finds the regulation to be invalid as arbitrary and capricious and promulgated outside the procedural requirements of the APA, it is not necessary for this Court to determine whether the regulation exceeds authority granted the Secretary under section 504. However, some concerns on this issue should be noted.

At the Court's request the parties have extensively briefed the meaning and effect of section 504 and the Court has undertaken independent research. The legislative history of the section focuses on discrimination against adults and older children and denial of access to federal programs. As far as can be determined, no congressional committee or member of the House or Senate ever even suggested that section 504 would be used to monitor medical treatment of defective newborn infants or establish standards for preserving a particular quality of life. No medical group appeared alert to the intrusion into medical practice which some doctors apprehend from such an undertaking, nor were

representatives of parents or spokesmen for religious beliefs that would be affected heard. Moreover, until the April, 1982, communication from President Reagan the record does not reflect any official indication that the section was subject to this interpretation during the many years it had by then already been in effect.

On the other hand, the statute on its face is open to a broad and all-inclusive interpretation. Section 504 requires that no recipient of federal financial assistance discriminate against handicapped individuals. A handicapped individual is defined in 29 U.S.C. § 706 as "any person who (i) has a physical or mental impairment which substantially limits one or more of such person's major life activities, (ii) has a record of such an impairment, or (iii) is regarded as having such an impairment." While the term "infant" in the regulation is not defined, at least some infants born with physical and mental defects may well fit within that broad definition.

Consequently whether the coverage of the regulation falls within or outside the authority of section 504 may well depend upon the manner in which section 504 is actually applied. Given the language of the statute and its similarity to other civil rights statutes which have been broadly read, it cannot be said that section 504 does not authorize some regulation of the provision of some types of medical care to handicapped newborns. At one extreme, it

is reasonable to suggest that section 504 prohibits denial of the most basic services, such as access to medical care, hospital facilities or food, to a mildly handicapped child whose parents want him to benefit from those services. But defendants and amici in support of defendants read the regulation and thus the statute far more broadly. It has been suggested by amici that the rule requires doctors and parents to undertake heroic measures to preserve for as long as possible, despite expense and a prognosis of certain death within months, the life of an anacephalic infant lacking all or part of the brain and with no hope of ever achieving even the most rudimentary form of consciousness.

Many would argue that had Congress intended section 504 to reach so far into such a sensitive area of moral and ethical concerns it would have given some evidence of that intent. Hopefully this will be clarified by further congressional action. In any event, cases such as Southeastern Community College v. Davis, 442 U.S. 397 (1979), and American Public Transit Association v. Lewis, 655 F.2d 1272 (D.C. Cir. 1981), suggest that section 504 was never intended by Congress to be applied blindly and without any consideration of the burdens and intrusions that might result. Yet the question of when, or whether, section 504 authorizes federal intervention in decisions regarding the treatment of handicapped newborns is a question which should await the actual application of the statute to a set

of particular circumstances. The instant case involves no parent or child plaintiff and no application of the rule to a specific case. It therefore is not an appropriate vehicle to consider the ramifications and scope of section 504. Toilet Goods Association v. Gardner, 387 U.S. 158, 163-166 (1967).

Constitutional Considerations

Finally, plaintiffs and amici have advanced two general constitutional challenges to the statute. Much for the same reason that this Court has not determined the scope of section 504's authority, it declines to reach these constitutional issues.

It is argued that the rule is impermissibly vague and overbroad. Given that neither "customary care," "infant," nor "discrimination due to handicap" are defined, there is some merit to the view that a physician attending a severely defective newborn may well be unable to determine what type of conduct the rule purports to require or prohibit. However, a broad regulation may be given content through its proper application, Waters v. Peterson, 495 F.2d 91, 99-100 (D.C. Cir. 1973), and review on this basis should await the actual application of the regulation to particular conduct. United States v. National Dairy Products Corp., 372 U.S. 29, 31-33 (1963).

Second, plaintiffs have suggested summarily that the regulation, by not supplying adequate procedural safeguards to any investigation resulting from a "hotline" complaint, is in conflict with an amorphous group of constitutional interests. These are described varingly throughout the papers as due process, right to privacy in the patient-physician relationship and the right to confidentiality of medical records. See Whalen v. Roe, 429 U.S. 589, 599-604 (1977). The exact nature of the rights plaintiffs seek to assert are uncertain as are the procedural safeguards alleged to be lacking. Again, in the absence of actual application of the regulation and a concrete set of facts this Court declines to hold in the abstract that the regulation violates such constitutional rights on its face. The Court notes, however, that to the extent the regulation is read to eliminate the role of the infant's parents in choosing an appropriate course of medical treatment, its application may in some cases infringe upon the interests outlined in cases such as Carey v. Population Services International, 431 U.S. 678, 684-685 (1977); Roe v. Wade, 410 U.S. 113, 152-153 (1973); and Griswold v. Connecticut, 381 U.S. 479, 484 (1965). However, no party is before the Court at present claiming such a constitutional interest and the issue cannot be joined in this case.[8/]

Conclusion

This regulation cannot be sustained. It is arbitrary and capricious. There may well be defects in medical procedures and hospital policies governing treatment of seriously disabled newborns in some hospitals. More fundamentally, the rising public debate over the role of physicians and family members in these difficult and sensitive situations where life may hang in the balance has raised issues which must eventually be faced at either the local or national level. The solution does not, however, lie in a hasty, ill-considered "hotline" informer rule. Government intervention into the difficult medical and human decisions that must be made in the delivery rooms and newborn intensive care units of our hospitals involves a profound change in the manner in which these decisions affecting the quality of life are made. Any intervention by an agency of the Federal Government should obviously reflect caution and sensitivity, given the present absence of a clear congressional directive. At the minimum, wide public comment prior to rulemaking is essential. Only by preserving this democratic process can good intentions be tempered by wisdom and experience.

An appropriate Order invalidating the interim final regulation is filed herewith.

Gerhard A. Gesell
UNITED STATES DISTRICT JUDGE

April 14, 1983.

1/ The case was presented on documents, depositions and affidavits filed with the Court and has been fully briefed and argued. Defendant has moved to dismiss and plaintiffs request declaratory and injunctive relief. With the agreement of the parties at the expedited hearing on the merits the case will be treated as if before the Court on cross-motions for summary judgment.

2/ For example, modern neonatal intensive care procedures can preserve the lives of grossly premature infants who are severely mentally retarded due to oxygen deprivation during birth. Prompt surgical treatment can save children with spina bifida (exposure of the spinal cord) from death but cannot save them from a life of partial paralysis, moderate to severe mental retardation, and complete dependence upon others for the simplest body functions. Modern techniques can preserve the lives of infants born with little or no brain (anacephalic) or digestive tract for weeks or even months. Surgery can correct the otherwise life-threatening cardiac and intestinal defects that commonly accompany Down's syndrome (mongolism) but cannot alter the mental retardation caused by Down's. See "Deciding to Forego Life-Sustaining Treatment," President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, March, 1983, pp. 181, 197-207.

3/ The following have filed briefs as amici curiae supporting plaintiffs or defendant:

Association for Retarded Citizens
American Coalition of Citizens with Disabilities
Down's Syndrome Congress
People First of Nebraska
Spina-Bifida Association of America
The Association for the Severely Handicapped

American Hospital Association

David G. McLone
Margaret Mahon
Lawrence J. Brodeur (guardian ad litem for Baby Doe)

Society of Critical Care Medicine

Disability Rights Education and Defense Fund

American Medical Association

4/ Channel 7 News in Boston aired the three-part expose. This film was relied on by the Secretary and has been viewed by the Court. It sensationalizes the issues underlying the regulation, relying in substantial part on events and studies already publicized, some going back several years.

5/ Dr. Parrott of Children's Hospital National Medical Center, which the Secretary considers an example of the standard of care desired, detailed by affidavit the serious consequences of such intrusion coupled with the suggestive nature of the posted signs.

6/ As Mr. Koslowe, counsel for defendant, stated at oral argument, the regulation is intended to produce "a change in how the doctors will reach their final judgments as to what to do or not to do in a given case, not their medical judgments, but whether they will stick to those medical judgments or allow those medical judgments to be overriden by parental objections."
Excerpt from hearing, April 8, 1983, p. __.

7/ The Secretary has failed to suggest, and the evidence before her did not support, any assertion that there has been a change in circumstances so that more lives are at risk presently than in the recent past or that the problem has somehow only for the first time become observable. Much of the information relied on by the Secretary was several years old.

8/ In addition to the principal issues discussed above, the parties raised a number of minor points which the Court finds either entirely lacked merit or are not appropriately before the Court for determination at this stage.

Plaintiffs argue that the regulation by authorizing some federal supervision of the medical treatment of newborns violates 42 U.S.C. § 1395, a section of the Medicare Act. That section on its face does not bar Congress from implementing controls over the practice of medicine under another statute.

Plaintiffs suggest that the regulation violates section 504 itself, because that section includes a requirement that certain regulations be presented to Congress 30 days before their effective date. Because the Court finds the March 7 regulation was promulgated in violation of applicable APA procedures, it is not necessary to reach this issue. Nor is it necessary, in the absence of some actual application of the regulation to a particular hospital, to determine as certain amici have argued whether various federal programs such as Medicare, Medicaid, and the Hill-Burton Act should be considered "federal financial assistance."

Finally, in an Amended Complaint filed two days before the scheduled final hearing on the merits, plaintiffs for the first time in this case requested this Court to review the May 18, 1982, notice as well as the March 7, 1983,

(footnote 8 continued)
regulation. While defendants have not had opportunity to respond to this new issue, no basis was presented for finding the notice invalid on its face. Plaintiffs do not allege the notice violated the APA but simply argue that, like the March 18 regulation, the notice is outside the scope of the authority granted the Secretary under section 504, violates the Medicare Act, and infringes upon constitutional rights in physician-patient privacy and confidentiality. As noted, the notice is not a violation of the Medicare Act and given its uncertain meaning and scope any review of its validity under section 504 and the Constitution must await its actual application to a particular set of facts. These issues should not be determined in the abstract.

IN THE UNITED STATES DISTRICT COURT

FOR THE DISTRICT OF COLUMBIA

AMERICAN ACADEMY OF PEDIATRICS,)
NATIONAL ASSOCIATION OF CHILDREN's)
HOSPITALS AND RELATED INSTITUTIONS,)
CHILDREN's HOSPITAL NATIONAL)
MEDICAL CENTER,)
)
Plaintiffs,)
)
v.) Civil Action No. 83-0774
)
MARGARET M. HECKLER,)
Secretary, Department of)
Health and Human Services,)
)
Defendant.)

ORDER AND DECLARATION

For reasons fully stated in the Court's Memorandum filed herewith, it is this 14 day of April, 1983,

ORDERED that defendant's motion to dismiss the complaint and amended complaint is denied; and it is further

DECLARED that defendant's March 7, 1983, interim final rule, 48 Fed. Reg. 9630, is arbitrary and capricious and promulgated in violation of the Administrative Procedure Act, and it is further

ORDERED that defendant shall promptly place a notice in the Federal Register advising that said interim final rule has been declared invalid and has no further force or effect, and it is further

ORDERED that applications for attorneys' fees and/or costs may be filed within 30 days of the time that this Order and Declaration becomes final.

Gerhard A. Gesell

UNITED STATES DISTRICT JUDGE

TAB 6

STATEMENT PAPER FOR HEARING

"Reauthorization of Child Abuse Prevention and Adoption Opportunities: Withholding of Care from Handicapped Infants in Hospitals"

David G. McLone, M.D., Ph.D.
Associate Professor of Surgery (Neurosurgery)
Northwestern University Medical School
Chicago, Illinois

and

Chairman,
Division of Pediatric Neurosurgery
Children's Memorial Hospital
Chicago, Illinois

My purpose in this presentation is to address some of the problems, paradoxes, and ambiguities surrounding the care of the child born with a serious handicap.

There is documentation that handicapped children have been denied life saving medical care and occasionally even basic nutrition: food and water. The extent of this problem is unknown. In the small, local sample provided by review of the last 200 patients with spina bifida referred for treatment, 10 children were found to have been denied prompt surgical therapy prior to transfer to our hospital. None of these had been denied food or water. If this sample be representative, then the incidence of delayed care may be on the order of some 5% of newborns with spina bifida.

Federal regulations now require that all handicapped children receive food, water, and customary medical care. Very few disagree with this in principle. Controversy arises from the interpretation of "customary medical care" in specific clinical contexts.

Most physicians would agree that newborns with life-threatening but completely remediable diseases should be treated as aggressively as necessary to ensure their survival and future health. Most physicians would also agree that newborns with irremediable, lethal malformations should be given nutrition and simple care. They should be made as comfortable as possible, and allowed to die in peace.

Opinion diverges sharply on proper care for the newborn with life-threatening disease when all possible treatment will ensure

survival with serious handicap. In this context, the parents, the physician, and the public weigh the patient's long-term survival, quality of life and possible eventual self-support. In this weighing, well-intentioned individuals of like morality may yet derive different conclusions.

I personally have had experience with well over 2000 handicapped children, principally those with spina bifida, hydrocephalus, prematurity, birth injury, and other birth anomalies. The overwhelming majority of these children have received prompt, often life-saving care. A small but significant number received less than that prior to transfer to our hospital; a form of euthanasia based upon withholding of available therapy and supportive care.

Some parents and physicians hope to find a medical and moral middle ground by inaction--"allowing nature to take its course". In the case of newborns with spina bifida, for example, they might provide food and water but deny prompt surgical repair of the open nervous system in the hope that the inevitable infection, meningoencephalitis, will prove rapidly fatal. This dereliction of responsibility fails for two reasons, among others. First, one half of the children will survive the infection and will still require additional, often more extensive, surgical care. Second, the more severe hydrocephalus and brain destruction caused by the infection markedly reduce the functional capacity of the 50% of patients who do survive. A policy of so-called "benign neglect" then is both offensive and ineffective.

Other parents and physicians seek to provide or deny therapy "rationally" by applying a set of medical "selection criteria" for identifying the newborns with spina bifida who are likely to have good clinical and functional outcome. Historically, these criteria were elaborated in Britain where many of the spina bifida patients are denied sustenance, are sedated, and are allowed to die. The British experience is entirely contrary to the recent experience in this country. However, because the majority of the medical literature dealing with management of spina bifida is from Great Britain and because many of the U.S. physicians who see only 1 or 2 such patients depend upon the literature for guidance, the "selection criteria" advocated by British physicians continue to be used, inappropriately, by some physicians in this country. In fact, medical advances have been so rapid that the functional outcome in unselected U.S. patients is now better than that predicted for the few "best" patients selected by the British criteria.

In my experience, decisions to passively euthanize severely handicapped children are almost never made because of callousness or amorality. Rather, those parents and physicians appear to have felt deep compassion for the child, deep concern for the suffering it would face, and overwhelming despair at its future prospects. The single most common reason for the denial of care was lack of recent information on available treatment and the outcome of that treatment. When confronted with recent developments in medical care and documented advances in patient outcome by physicians with substantial experience in the care of

these children, most of these parents and physicians were able to resolve their doubts and decide in favor of treating the child. In most cases then, continuing education of the public and professionals provided the solution to the dilemma.

Since information availability and public/professional education are so important in salvaging the handicapped child, a number of steps have been taken. Progress is being made to keep the medical literature current by documenting the recent advances in care of these patients. State and national parent support groups like The Spina Bifida Association of America are forming to provide parents and physicians first confronting this problem with informational, emotional, and financial support at the time the critical choices must be made. Government and media awareness programs have all contributed to a reduction in the number of neonates with spina bifida who are denied treatment. The developing pediatric tertiary care centers and available expert opinion should further decrease the level of ignorance. Obviously, we as a group with a vested interest in the welfare of the children feel much more can be done.

I have become increasingly concerned about the paradox presented by our government. On the one hand, we are told by the executive branch through HHS and the Justice Department that no handicapped child can be denied food, water, or customary medical care. Mechansims are put in place to monitor, through signs and hot lines, how the medical profession deals with this problem. At the same time, the funds needed to deal with the cause of these handicaps and to habilitate these handicapped individuals

TAB 7

From: Spina Bifida Associationof America
343 S. Dearborn, Suite 117
Chicago, IL 60604
Contact: Kent Smith
Phone: 312/663-1562

Washington Contact
Martin Holtz
Phone: 301/594-0143

FOR IMMEDIATE RELEASE

Spina Bifida Association of America Supports New "Baby Doe" Regulations

The Spina Bifida Association of America supports the proposed "Baby Doe" regulations reissued by the Dept. of Health and Human Services. The Association feels strongly that this federal presence is needed to guarantee equal treatment. The Association has found discrimination against many of those 8000 born each year with Spina Bifida—a rate of one child an hour.

All too often, parents of a new-born child with Spina Bifida are expected to make rational life and death decisions when what was expected to be a joyous occasion has instead become an occasion for confronting the unknown. Because this decision must be made quickly and under stress, parents turn to their physicians for guidance. Yet that physician may never have had a close personal experience with a disabled child or adult. Suddenly a decision must be made and the deck is stacked against the infant with a disability. These regulations will unstack the deck.

Clearly, new parents of a disabled child need information on the disability and its treatment, as well as the names of agencies and support groups available to assist a family unit.

In 1979, the Spina Bifida Association of America established a policy that encourages early evaluation and medical/surgical treatment of every infant with Spina Bifida by professionals experienced in their treatment and care. Between 80 and 90% of infants born today with Spina Bifida can lead productive lives if they receive immediate attention at medical centers familiar with their treatment. The Association also operates an adoption information/referral program for parents who feel unprepared to raise a child with a physical disability. Established 18 months ago, this program has placed 51 children and has a waiting list of 40 parents needing children to adopt.

The routine referral of parents, and physicians as well, to groups who deal directly with the disabled, would do much to erase the pessimistic appraisals of those individuals unfamiliar with the potential of the disabled. It is time to realize that discrimination against the disabled is often based on ignorance and is unjustifiable.

TAB 8

HHS NEWS

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

Thursday, June 30, 1983

STATEMENT BY C. EVERETT KOOP, M.D.
SURGEON GENERAL OF THE UNITED STATES

On behalf of HHS Secretary Margaret M. Heckler, I am announcing that the Department of Health and Human Services will today issue a regulation protecting handicapped infants from illegal discrimination in receiving health care. By doing so, Secretary Heckler reaffirms the commitment of President Reagan and this Administration to effective enforcement of the federal law prohibiting discrimination on the basis of handicap.

The regulation we are issuing today implements the equal treatment, non-discrimination guarantees of the Rehabilitation Act of 1973 to handicapped newborn babies.

The proposed rule would reestablish, with several important revisions, the requirements of our interim final rule of March 7, 1983. These revisions clarify the scope and intent of the regulation, direct the reporting mechanism to medical personnel as those most capable of judging whether appropriate care is being denied, and more fully involve state child protection service agencies.

Hospitals which receive federal funding, including funds through Medicare and Medicaid, must post a notice providing telephone numbers of local child protection service agencies and the Department of Health and Human Services to which alleged discrimination on the basis of handicap may be reported. This new regulation is being issued in the form of a notice of proposed rulemaking with a 60-day public comment period. Our proposal is accompanied by an invitation for the public to comment on the full range of issues including alternative and additional enforcement methods.

The notice includes an extensive preamble and supplement clarifying the regulation with specific examples of appropriate and inappropriate application of the regulation to qualified infants.

This regulation does not interfere with medical judgment concerning which treatment is beneficial. Section 504 does not compel medical personnel to attempt to perform impossible or futile acts or therapies. Thus, it does not require the imposition of futile treatment which merely temporarily prolongs the process of dying of an infant born terminally ill.

Section 504 preserves the decision-making process customarily undertaken by physicians in any treatment decision. It is only when non-medical considerations, such as subjective judgments that an unrelated handicap makes a person's life not worth living, are interjected in the decision-making process that the Section 504 concerns arise.

-More-

The law is clear on this matter. Discrimination on the basis of handicap in federally funded programs is illegal. The need for effective procedures for detecting and preventing life-threatening violations of the law is compelling. For even a single infant to die due to lack of an adequate notice and complaint procedure is unacceptable.

By announcing this proposed rule today, the Reagan Administration once again commits itself to safeguarding the lives--and the legally protected rights--of handicapped infants in the United States.

As Secretary Heckler has stated: "For too long, our society ignored the rights of the handicapped. As we enter the 'Decade of Disabled Persons,' now that we've finally become more sensitive and responsive to older handicapped persons, how we can tolerate the denial of those same rights to handicapped infants?

"Within each and every child there is something unique. How much poorer in spirit would we be if basic sustenance had been denied at birth to the many handicapped persons who today lead productive lives? How much would have been lost?"

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Tab 9 of report is in next folder

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