

Policy Analysis:

Caroline Pryce Walker Conquer Childhood Cancer Act of 2008

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SW3330: Social Welfare Policy Programs & Issues

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Caroline Pryce Walker Conquer Childhood Cancer Act of 2008 aims to amend the Public Health Service Act to include pediatric cancer. This amendment to the Public Service Act, “advances medical research and treatments into pediatric cancers, ensures patients and families have access to information regarding pediatric cancers and current treatments for such cancers, establishes a national childhood cancer registry, and promote public awareness of pediatric cancer”(“Caroline Pryce Childhood Conquer Childhood Cancer Act of 2008”, p.1). The policy hopes to decrease the statistics of childhood cancer through accomplishing these goals.

The purpose of this paper is to analyze the Caroline Pryce Walker Conquer Childhood Cancer Act of 2008 first analyzing the social problem and development of the policy. This will be done by discussing the purpose of implementing this policy and the process of policy creation, including an explanation of why childhood cancer is a social problem, the goals of the policy, and the individuals and groups supporting and opposing this policy. The second part of the paper aims to analyze the policy implementation by discussing the achievements and inadequacies of the goals, implementation problems and issues, unintended and latent consequences, and suggested revisions.

Analysis of the Social Problem and the Development of the Policy

The purpose of this policy is to advance medical research for childhood cancer and increase awareness for the patients and families involved, as well as public awareness of the magnitude of the issue of childhood cancer. The policy was created to amend the Public Service Act to include areas of pediatric cancer. The need for a policy regarding childhood cancer prior to the enactment of the Caroline Pryce Conquers Childhood Cancer Act of 2008 was the overwhelming social problem of childhood cancer. According to the “Caroline Pryce Childhood Conquer Childhood Cancer Act of 2008” (2008), the need for enactment of this policy was that

cancer was the leading cause of death in U.S. Children between infancy and 15 years old and in 2007 10,400 new cases of pediatric cancer were diagnosed (p.4). A social worker with Kids Path Hospice out of Greensboro, NC says that, “the need for awareness and research is enormous and though many children are treated and put in remission for the disease there are still those handfuls that end up in Hospice and lose their lives far to early”(Anonymous, personal communication, Dec. 7, 2009). Once children are diagnosed they have a choice of treatments that include chemotherapy, surgery and/ or radiation therapy (Prucha, 1999, p. 183). With the diagnosis of pediatric cancer come many financial burdens. The financial impact is great even for families who have adequate health insurance, cost of cancers include: travel costs to hospitals that could be hundreds of miles away, phone bills from long-distance calling, psychotherapy for individuals and families, private tutors, childcare for the sibling without pediatric cancer (Fromer, 1995, p. 139-141). Not only is there a financial struggle with the families, but with the state of our economy in 2007 which was prior to the enactment of this policy, budget cuts were being made which included greatly reducing the funding for pediatric cancer research (Charney). In 2007, “The National Cancer Institute” states it federal budget was \$4.6 billion and all 12 major groups of pediatric cancers combined received less than 3% of that budget. Charney states that due to these budget cuts, “the Children’s Oncology Group (COG), the world’s pre-eminent childhood cancer research organization, has been forced to put 20 new studies on hold and decrease enrollment in new clinical trials by more than 400 children next year”. The social problem of childhood cancer and the social conditions of the economic downturn in the economy cutting funding for pediatric cancer research contributed to the need for this policy.

Caroline Pryce Walker Conquer Childhood Cancer Act of 2008 has three stated goals. The first is for support of pediatric cancer research and other activities related to pediatric cancer to be encouraged (Legislative History, p. 2). This goal is aiming to further research for treatment of childhood cancers, such as brain tumors and neuroblastoma because treatments are inadequate and develop Federal support for activities leading to an enhanced understanding of childhood cancers and treatments that are less toxic and more effective (“Caroline Pryce Childhood Conquer Childhood Cancer Act of 2008”). The second stated goal is to establish a comprehensive national childhood cancer registry (“Caroline Pryce Childhood Conquer Childhood Cancer Act of 2008”, p. 2). The registry would make it easier to access pediatric cancer patients and their families which would help accomplish the third stated goal of the policy which is to provide informational services to patients and families affected by childhood cancer (“Caroline Pryce Childhood Conquer Childhood Cancer Act of 2008”, p. 2). These services would provide informational, educational, and support resources for pediatric cancer patients and families as well as improve the awareness and communication of the public regarding research and treatments for pediatric cancer and their families ("Curesearch praises passage").

An unstated goal of this policy is that it is the hope that the money appropriated would do the majority of the funding for pediatric cancer research. These appropriations would provide more clinical trials and it is an unstated goal of the policy to be able to provide more clinical trials so that most children with pediatric cancer have access to them ("Rock against cancer," 2008). Most of all, it seems that the policy main goal without stating it is to find the cause of cancer and cures for childhood cancer.

The key individual that was involved in the formulation of this policy was Congresswoman Deborah Pryce. Deborah Pryce is the mother of Caroline Pryce Walker who

passed away in 1999 at age nine from neuroblastoma and who the bill is named in memory for. The name of the bill shows Congresswoman Pryce hard work to fight childhood cancer considering the bill was originally called the Conquer Childhood Cancer Act, but was amended by the House Committee to be named after Congresswoman Pryce's daughter ("Curesearch praises passage"). Pryce was the original author and sponsor of the bill with co-sponsorship from Congressman Chris Van Hollen. Groups supporting this policy include Curesearch National Childhood Cancer Foundation, Hope Street Kids, People Against Childhood Cancer, groups and institutes that are doing the research for childhood cancer. These specific groups are groups that have a lot of media about the policy on their websites before and after the implementation of the policy. Hope Street Kids is an organization that was founded by Congresswoman Deborah Pryce and Randy Walker just after their daughter Caroline passed. The mission of Hope Street Kids is "to eliminate childhood cancer through pioneering research, advocacy, and education ("Hope street kids"). The goal of all of these groups is to decrease the numbers of childhood cancer in the United States which makes their support of the bill obvious.

The bill passed with unanimous votes from the House and the Senate, but Senator Coburn openly objected to the bill. During his floor speech he states, "But I will tell you, we will get less, not more, by doing this in terms of the research and the benefit for the children who have childhood cancer in this country"("H.R. 1553"). His reservations are because of the amount of money appropriated per year for childhood cancer and believes that the money could be spent for other childhood diseases as well and would save more lives ("H.R. 1553"). He allowed for passage of the bill because of a personal relationship with Deborah Pryce and her child who passed away. Senator Coburn may be publicly opposed to the bill, but no known groups are found to be opposed to the bill.

There are no specific ethnic, gender, and sexual orientation issues relevant to the purpose of this policy. During the implementation of the policy, an amendment was made to include that services and information through grants under the policy be culturally and linguistically appropriate as needed by patients and families affected by childhood cancer (“Caroline Pryce Childhood Conquer Childhood Cancer Act of 2008”). This amendment requires equality through the bill and its services.

Policy Implementation and Analysis

This bill was signed in July of 2008 and the funding appropriations for the bill have not been met in order to achieve the goals of the policy. As of December 9, 2009 the House passed omnibus appropriations conference report (HR 3288) that shows that \$3 million will go to the Centers for Disease Control for a pediatric cancer registry, \$1 million for informational services to patients and families affected by childhood cancer authorized under the Caroline Pryce Walker Conquer Childhood Cancer Act, and no appropriations for pediatric cancer research as authorized by the Caroline Pryce Walker Conquer Childhood Cancer Act (“People Against Childhood Cancer”). These appropriations are for the 2010 Fiscal year and are only appropriating \$4 million dollars as opposed to \$30 million dollars a year as stated in the policy.

Implementation problems and issues consisted of issues with the bill and the amount of appropriations that would be authorized under the bill when there is already an amount of federal money and private grants that go to pediatric cancer research and would be \$30 million taken away from other childhood diseases (“H.R. 1553”). Another implementation concern was that the Center for Disease Control has a registry and The National Endowment for the Humanities has two registries, which seems to make funding for a registry unrealistic (“H.R. 1553”). Though, the policy states that the goal is to make a comprehensive registry.

There weren't that many unintended or latent consequences of this policy. One latent consequence would be that the public may assume that their tax dollars will be raised for the funding for childhood cancer when this bill is actually budget neutral and shifts dollars from within rather than creating new spending (Charney). Not only does the public wonder where the money comes from, but also why the policy is suggesting \$30 million dollars per year towards only pediatric cancer. This is an unintended consequence of the policy because the policy had been centered on childhood cancer from the beginning and most involved have a personal connection to childhood cancer which would eliminate the possibility of adding other diseases. The magnitude of these unintended and latent consequences is fairly big because these consequences are coming into play during talks of the budget for the policy (Charney).

Benefits of the Caroline Pryce Walker Conquers Childhood Cancer Act of 2008 in its present form is that it's not only focused on finding research for a cure for childhood cancer, but is developing more resources for the patients and families affected by childhood cancer ("Caroline Pryce Childhood Conquer Childhood Cancer Act of 2008"). The current policies goals are clearly stated and achievable with the appropriate amount of funding. Sarah McCrary, a survivor of childhood leukemia and now a senior in college at Appalachian State University stated, "I see the policy being beneficial for providing research grants, to hopefully save the lives of many children, as I'm sure research saved mine. I also feel as though public awareness would be beneficial in "normalizing" cancer, because I remember being extremely embarrassed until my freshman year in college about my childhood cancer experience"(S. McCrary, personal communication, December 6, 2009). The goals currently proposed will benefit the lives of pediatric cancer patients and their families while searching to find a cure through research and clinical trials ("Rock against cancer," 2008). Unfortunately as of right now the policy hasn't

proven to be very useful towards fighting childhood cancer. Though the goals seem beneficial, they cannot be met without the correct funding and that is where the policy is running into problems.

Revisions of the policy that have been suggested have been based around funding. Senator Latta of Bowling Green suggested for \$10 million dollars a year in federal money to go to childhood cancer as opposed to the \$30 million dollars a year ("Clyde cancer cluster," 2009). The rationale for this particular revision is that it is proposing a new amount of money that could more easily be funded through the existing budget and new appropriations. This revision could be achieved by writing an amendment to the Labor, Health, and Human Services Appropriations bill, which Senator Latta has already done ("Clyde cancer cluster," 2009). Another step could be to submit amendments for the policy to change its appropriations of funds being more specific about how much money would be needed to successfully achieve stated goals.

In conclusion the Caroline Pryce Walker Conquer Childhood Cancer Act of 2008 aims to advance research and treatments of childhood cancer while providing resources for those affected by childhood cancer. This paper has analyzed the policy from the beginning of implementation to suggestions for revisions as the policy stands today. Overall, it is most important that the policy is advocated for and that funding is figured out so that the Caroline Pryce Walker Act of 2008 can see success in the near future.

Appendix A

UNITED STATES PUBLIC LAWS
110th Congress 2nd Session
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PUBLIC LAW 110-285 [H.R. 1553]
JULY 29, 2008
CAROLINE PRYCE WALKER CONQUER CHILDHOOD CANCER ACT OF 2008

110 P.L. 285; 122 Stat. 2628; 2008 Enacted H.R. 1553; 110 Enacted H.R. 1553

BILL TRACKING REPORT: [110 Bill Tracking H.R. 1553](#)
FULL TEXT VERSIONS(S): [110 H.R. 1553](#)
CIS LEGIS. HISTORY DOCUMENT: [110 CIS Legis. Hist. P.L. 285](#)

An Act

To amend the Public Health Service Act to advance medical research and treatments into pediatric cancers, ensure patients and families have access to information regarding pediatric cancers and current treatments for such cancers, establish a national childhood cancer registry, and promote public awareness of pediatric cancer.

Be it enacted by the Senate and House of Representatives of the United States of America in Congress <<NOTE: Caroline Pryce Walker Conquer Childhood Cancer Act of 2008. [42 USC 201](#) note.>> assembled,

SECTION 1. SHORT TITLE.

This Act may be cited as the "Caroline Pryce Walker Conquer Childhood Cancer Act of 2008".

SEC. 2. <<NOTE: [42 USC 280e-3a](#) note.>> FINDINGS.

Congress makes the following findings:

- (1) Cancer kills more children than any other disease.
- (2) Each year cancer kills more children between 1 and 20 years of age than asthma, diabetes, cystic fibrosis, and AIDS, combined.
- (3) Every year, over 12,500 young people are diagnosed with cancer.
- (4) Each year about 2,300 children and teenagers die from cancer.
- (5) One in every 330 Americans develops cancer before age 20.
- (6) Some forms of childhood cancer have proven to be so resistant that even in spite of the great

research strides made, most of those children die. Up to 75 percent of the children with cancer can now be cured.

(7) The causes of most childhood cancers are not yet known.

(8) Childhood cancers are mostly those of the white blood cells (leukemias), brain, bone, the lymphatic system, and tumors of the muscles, kidneys, and nervous system. Each of these behaves differently, but all are characterized by an uncontrolled proliferation of abnormal cells.

(9) Eighty percent of the children who are diagnosed with cancer have disease which has already spread to distant sites in the body.

(10) Ninety percent of children with a form of pediatric cancer are treated at one of the more than 200 Children's Oncology Group member institutions throughout the United States.

SEC. 3. <<NOTE: [42 USC 280e-3a](#) note.>> PURPOSES.

It is the purpose of this Act to authorize appropriations to--

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(1) encourage the support for pediatric cancer research and other activities related to pediatric cancer;

(2) establish a comprehensive national childhood cancer registry; and

(3) provide informational services to patients and families affected by childhood cancer.

SEC. 4. PEDIATRIC CANCER RESEARCH AND AWARENESS; NATIONAL CHILDHOOD CANCER REGISTRY.

(a) Pediatric Cancer Research and Awareness.--Subpart 1 of part C of title IV of the Public Health Service Act ([42 U.S.C. 285](#) et seq.) is amended by adding at the end the following:

"SEC. 417E. <<NOTE: [42 USC 285a-11](#).>> PEDIATRIC CANCER RESEARCH AND AWARENESS.

"(a) Pediatric Cancer Research.--

"(1) Programs of research excellence in pediatric cancer.-- The Secretary, in collaboration with the Director of NIH and other Federal agencies with interest in prevention and treatment of pediatric cancer, shall continue to enhance, expand, and intensify pediatric cancer research and other activities related to pediatric cancer, including therapeutically applicable research to generate effective treatments, pediatric preclinical testing, and pediatric clinical trials through National Cancer Institute-supported pediatric cancer clinical trial groups and their member institutions. In enhancing, expanding, and intensifying such research and other activities, the Secretary is encouraged to take into consideration the application of such research and other activities for minority, health disparity, and medically underserved communities. For purposes of this section, the term 'pediatric cancer research' means research on the causes, prevention, diagnosis, recognition, treatment, and long-term effects of pediatric cancer.

"(2) Peer review requirements.--All grants awarded under this subsection shall be awarded in accordance with section 492.

"(b) Public Awareness of Pediatric Cancers and Available Treatments and Research.--

"(1) In general.--The Secretary may award grants to childhood cancer professional and direct

service organizations for the expansion and widespread implementation of--

"(A) activities that provide available information on treatment protocols to ensure early access to the best available therapies and clinical trials for pediatric cancers;

"(B) activities that provide available information on the late effects of pediatric cancer treatment to ensure access to necessary long-term medical and psychological care; and

"(C) direct resource services such as educational outreach for parents, peer-to-peer and parent-to-parent support networks, information on school re-entry and postsecondary education, and resource directories or referral services for financial assistance, psychological counseling, and other support services. In awarding grants under this paragraph, the Secretary is encouraged to take into consideration the extent to which an entity would use such grant for purposes of making activities and services described in this paragraph available to minority, health disparity, and medically underserved communities.

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"(2) Performance measurement, transparency, and accountability.--For each grant awarded under this subsection, the Secretary shall develop and implement metrics-based performance measures to assess the effectiveness of activities funded under such grant.

"(3) Informational requirements.--Any information made available pursuant to a grant awarded under paragraph (1) shall be--

"(A) culturally and linguistically appropriate as needed by patients and families affected by childhood cancer; and

"(B) approved by the Secretary.

"(c) Rule of Construction.--Nothing in this section shall be construed as being inconsistent with the goals and purposes of the Minority Health and Health Disparities Research and Education Act of 2000 ([42 U.S.C. 202](#) note).

"(d) Authorization of Appropriations.--For purposes of carrying out this section and section 399E-1, there are authorized to be appropriated \$ 30,000,000 for each of fiscal years 2009 through 2013. Such authorization of appropriations is in addition to the authorization of appropriations established in section 402A with respect to such purpose. Funds appropriated under this subsection shall remain available until expended."

(b) National Childhood Cancer Registry.--Part M of title III of the Public Health Service Act ([42 U.S.C. 280e](#) et seq.) is amended--

(1) by inserting after section 399E the following:

"SEC. 399E-1. <<NOTE: [42 USC 280e-3a](#).>> NATIONAL CHILDHOOD CANCER REGISTRY.

"(a) In General.--The <<NOTE: Grants.>> Secretary, acting through the Director of the Centers for Disease Control and Prevention, shall award a grant to enhance and expand infrastructure to track the epidemiology of pediatric cancer into a comprehensive nationwide registry of actual occurrences of pediatric cancer. Such registry shall be updated to include an actual occurrence within weeks of the date of such occurrence.

"(b) Informed Consent and Privacy Requirements and Coordination With Existing Programs.--The registry established pursuant to subsection (a) shall be subject to [section 552a of title 5, United States Code](#), the regulations promulgated under section 264(c) of the Health Insurance

Portability and Accountability Act of 1996, applicable Federal and State informed consent regulations, any other applicable Federal and State laws relating to the privacy of patient information, and section 399B(d)(4) of this Act."; and

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(2) in section 399F(a), <<NOTE: [42 USC 280e-4](#).>> by inserting "(other than section 399E-1)" after "this part".

Approved July 29, 2008.

HISTORY:

LEGISLATIVE HISTORY--H.R. 1553 (S. 911):

HOUSE REPORTS: No. 110-706 (Comm. on Energy and Commerce).

CONGRESSIONAL RECORD:

Vol. 154 (2008):

June 11, 12, considered and passed House.

July 16, considered and passed Senate.

Appendix B

References

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