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**TESTIMONY ON SENATE BILL 1051**  
**PRESENTED TO THE HOUSE JUDICIARY COMMITTEE'S TASK FORCE**  
**ON GUARDIANSHIPS AND ESTATES**

**JULY 7, 1998**

Good morning Representative Schuler and other members of the Task Force on Guardianships and Estates. My name is Jonna Revitz and I am the Legislative Assistant at the American Civil Liberties Union of Pennsylvania. I want to thank you for providing the ACLU with this opportunity to express our support for Senate Bill 1051.

The ACLU joins the many other advocates and organizations who understand the need for legislation that establishes standby guardianships here in Pennsylvania. Such legislation is crucial to a parent who is suffering from HIV/AIDS, cancer, diabetes, or any other chronic or fatal illness. Prior to my employment with the ACLU, I worked as a counselor on the Pennsylvania Department of Health AIDS Factline. This hotline serves as an outlet for people with concerns about HIV, as a resource for those with questions about treatment and care, and as a channel by which consumers who have encountered difficulties due to their HIV status can voice their frustrations. My experience counseling those that have HIV, or even those that are concerned that they may be at risk for HIV, documents that barriers to healthcare and day-to-day living arise continuously. Among the many emotional, financial and logistical issues that occur

for someone with HIV, relevant to Senate Bill 1051 are concerns that someone with HIV has regarding her or his family. Repeatedly, callers of the hotline voiced fear and apprehension about the effects that a compromised immune system would have on their families, specifically their children. Decision-making for a parent with a disease such as HIV can become complicated and crucial. From a counseling perspective, standby guardianship laws could make the often unpredictability of having an illness like HIV/AIDS easier to bear when a parent can plan for the future of her or his children.

In order to provide a better understanding of the legal status of this form of guardianship, I would like to review existing standby guardianship laws in this country. Currently, nine states have enacted standby guardianship legislation. Florida enacted the first standby guardianship law in 1981. Since then New York, Maryland, Connecticut, Illinois, Massachusetts, North Carolina, New Jersey, and most recently Wisconsin have also enacted laws. Each of these states has responded to the problems encountered by a single parent who has a chronic or fatal illness, who wants to arrange for the best care and custody of her or his child during those times when the illness makes it difficult to provide adequate care, but who does not wish to relinquish his or her parental rights. Traditional guardianship laws have been found to be inadequate to address the desires of such parents or the needs of the children of such parents.

Congress has recognized the benefits of this kind of legislation. Last year, Congress passed the Federal Adoption and Safe Families Act of 1997 (Public Law 105-89). Section 403 of that Act states:

Sec. 403. SENSE OF CONGRESS REGARDING STANDBY GUARDIANSHIP.

It is the sense of Congress that the States have in effect laws and procedures that permit any parent who is chronically ill or near death without surrendering parental rights, to designate a standby guardian for the parent's minor children, whose authority would take effect upon --

- (1) the death of the parent;
- (2) the mental incapacity of the parent; or
- (3) the physical debilitation and consent of the parent.

While Congress may not have mandated that states enact standby guardianship legislation, it did acknowledge that such legislation is an important component of a comprehensive policy to provide for the varied needs of the children whose parents are incapable of providing adequate care.

Similar legislation was even considered in the Pennsylvania House of Representatives in 1994. In the fall of that year, the House overwhelmingly approved House Bill 2500. Unfortunately, it was not acted upon by the Senate before the end of that session. House Bill 2500 could be considered an early version of that which is before you today. Senate Bill 1051 reflects many positive changes that have been made over the course of further consideration and drafting of a standby guardianship law for Pennsylvania.

The ACLU believes that Senate Bill 1051 will fill a gap in existing Pennsylvania law. We think that Senate Bill 1051 does that in a way that preserves parental rights, encourages responsible planning by parents with chronic or fatal illnesses, and meets the needs of children without further burdening foster care agencies. We have had the privilege of being asked to assist with reviewing and refining the legislation that is before you today and we think that it is a



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## **TESTIMONY ON S.B. 1051**

presented to the

House Judiciary Committee's Task Force on Guardianships and Estates

by

Jane E. Philips  
Director of Advocacy

July 7, 1998

Testimony of Jane Phillips, Director of Advocacy  
on Behalf of Family Service of Lancaster County  
to the House Judiciary Committee's Task Force on Guardianships and Estates  
Regarding Senate Bill 1051

Good afternoon. Thank you for inviting me to testify in support of Senate Bill 1051, The Standby Guardianship Act. My name is Jane Phillips and I am the Director of Advocacy with Family Service. I welcome the opportunity to speak on behalf of families and children who could be helped by this legislation.

Family Service is a private, not-for-profit social service agency working with families in Lancaster County for over 90 years. Because the agency offers a very wide variety of services, including adoption, substance abuse treatment, domestic violence and others, we are aware of the broadest spectrum of issues affecting families. My function as Director of Advocacy is to identify issues that are negatively affecting our clients and to improve the situation.

In 1992, two very frightened mothers asked us for a service that did not then exist. They were requesting periodic placements for their children when they were too ill to parent. Their biggest fear was that by utilizing any placement services they might lose custody of their children. Their fear accurately reflects the perceptions of many parents with terminal diseases and especially those who are stigmatized by their infection with HIV. In addition to this fear, these mothers were experiencing a nearly universal reaction of patients with terminal diseases.<sup>1</sup>

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<sup>1</sup>Nearly all patients with terminal diseases use denial of their impending death to maintain as much control and hope as possible. In many respects, this denial is a healthy defense, however, in parents this normal defense is handicapped by the guilt and anxiety of knowing their children will be orphaned. For clients with HIV, the "natural" denial mechanism is further handicapped by the fear of family rejection, community hostility and institutional discrimination.

This fear is particularly strong in relation to legal and government social services. As a result, parents hide their HIV status fearing that it will be used as a lever to prematurely or wrongfully remove their children. They elude assistance until, tragically, it is too late for good planning for their children's futures. One example of this was a 36 year old parent, who recently died of renal failure. Fearful of formal systems, she lapsed into unconsciousness before her child was securely placed.

Currently, Family Service provides counseling, respite/foster care and legal services to AIDS Affected children and their families. We began this service in 1994 as an answer to the mothers (mentioned earlier) and after a broad study of the needs of these families. In addition to our program, we confer closely with other service providers in Lancaster County and across the state. Our experience with these families is replicated with these providers.

AIDS affected families come from diverse racial and ethnic backgrounds, educational and social levels. In spite of this diversity, however, they nearly all share the range of fears described above and at present, for many, the current legal options are unworkable. If they are already engaged with an agency, they often break off connection at the point they fear that "the legal system" may take control of their children. If they aren't engaged with any agency, they often opt for an informal arrangement that doesn't guarantee that their child has all of the protections they need, or that the child will actually stay in the home they chose. This wariness of becoming involved with the "legal system" persists even though we are able to offer pro bono services from local attorneys.

The Standby Guardianship procedure is a viable alternative for these parents. Although placement of one's children will never be easy to face, we anticipate that the necessary planning (and commitment to act) will be greatly facilitated by the availability of this process.

good piece of legislation. We hope that you will move Senate Bill 1051 forward so that it may be enacted in 1998.