

**WISCONSIN DEPARTMENT OF HEALTH AND FAMILY SERVICES  
TESTIMONY BEFORE THE HOUSE WAYS AND MEANS COMMITTEE  
SUBCOMMITTEE ON HUMAN RESOURCES**

**Deputy Secretary Roberta Harris**

*May 18, 2005*

Thank you for this opportunity to provide information to the committee on this very important topic. Children in the child welfare system, whether in their own homes or in some form of out-of-home care, are some of the most vulnerable children in our nation. It is critical that child welfare professionals, child advocates, medical professionals, elected representatives, and the general public do all that we can to ensure that these children are protected from any additional trauma.

It is not my intent to denigrate the important work reflected in most legitimate medical and other research. Clearly, significant advances are made every day as a result of well designed and implemented research studies.

In Wisconsin, we have not approved medical research on foster children as a class, or any subgroup of foster children, because we believe it is our responsibility to provide as much of a safe, nurturing environment for the children in foster care as possible. The types of research that have unfortunately occurred in our nation in the past would also make it difficult for us to earn the trust and confidence of the families we are seeking to help, who desperately need the services we can offer.

As such, I would like to offer our comments on the topic related to the lack of homogeneity of foster children, the problems with voluntary participation on the part of families, and the legal realities of our authority to consent to such research.

1. Lack of Homogeneity

Research, whether medical or otherwise, should not be limited to a particular group, unless there is some homogeneity within that group that is unique. In this regard, there is very little – if anything – that can be regarded as homogenous among children in foster care, other than that they have been removed from their homes; in most cases, involuntarily.

Children in foster care are there for a variety of reasons: some have been abused or neglected or had siblings who were abused or neglected; some have mental health issues of a severe nature, sometimes as a result of the trauma of being removed from their homes, parents, and siblings; some are medically fragile or developmentally disabled with special care and treatment needs that cannot be provided by their parents; some children are delinquent. Certainly, many are from low income families.

Recent news articles have indicated that several states have allowed foster children to participate in medical studies related to research endeavors dealing with Acquired Immunodeficiency Syndrome (AIDS). It is certainly true that some children in foster care have HIV or AIDS. It is also true that many children **not** in foster care have HIV or AIDS. To focus a study, then, on medication related to that condition only on children in foster care, when there are known potential negative effects of those medications, certainly leads to a perception that somehow foster children are valued less than other children.

## 2. Voluntary Nature of Participation

In Wisconsin, our position on the involvement of foster children in research, especially medical research, is based in large part on a variety of ethical codes related to medicine, social work, and mental health. A major document forming the basis of our position is embodied in the The World Medical Association Declaration of Helsinki, originally adopted in 1964, and as amended in 1975, 1983, 1989, 1996, 2000, 2002, and 2004, which places great emphasis on the voluntary nature of participation in research.

Paragraph 1 of that document states, in part, that “. . . Some research populations are vulnerable and need special protection. The particular needs of the economically and medically disadvantaged must be recognized. Special attention is also required for those who cannot give or refuse consent for themselves, for those who may be subject to giving consent under duress, . . .”

We believe the children in our child welfare system are vulnerable based upon the trauma within their home, along with the distress that can be caused from being removed from their family and placed into foster care. We believe it is our role to do what we can to help ensure the safety and welfare of the children in our system. In addition, as I testified to earlier, many children in the child welfare system are economically disadvantaged. We must recognize their needs and protect the family from giving consent under duress.

To continue from the World Medical Association Declaration of Helsinki, Paragraph 20 states that “The subjects must be volunteers and informed participants in the research project.”

Paragraph 23 states “When obtaining informed consent for the research project the physician should be particularly cautious if the subject is in a dependent relationship with the physician or may consent under duress. In that case the informed consent should be obtained by a well-informed physician who is not engaged in the investigation and who is completely independent of this relationship.”

Paragraph 24 states that “For a research subject who is legally incompetent, physically or mentally incapable of giving consent or is a legally incompetent minor, the investigator must obtain informed consent from the legally authorized representative in accordance with applicable law. These groups should not be included in research unless the research is necessary to promote the health of the population represented and this research cannot instead be performed on legally competent persons.”

Paragraph 25 states that “When a subject deemed legally incompetent, such as a minor child, is able to give assent to decisions about participation in research, the investigator must obtain that assent in addition to the consent of the legally authorized representative.”

I raise these issues related to consent because, to a certain extent, they go to the heart of the nature of the relationships among children, their families, and the child welfare system. In the context noted above, two definitions of the term “voluntary” should be carefully considered:

Voluntary: Done, given, or proceeding from the free or unconstrained will of a person. [The World Book Dictionary]

Voluntary: Acting or performed without external persuasion or compulsion. [The American Heritage Dictionary of the English Language]

With the exception of some of the small percent of voluntary placements, out-of-home placements are ordered by the court. As such, when the agency that has the authority to determine when a child will be returned to the parent recommends that the parent approve the child's participation in medical research, at least on a perceived basis, it is questionable whether the parent would feel that his or her approval is truly voluntary.

### 3. Legal Status

This brings us to the issue of who can approve the involvement of a foster child in any type of research, medical or otherwise. In the child welfare system, there are generally four types of legal relationship between a child and an individual or agency acting on that child's behalf. These are physical custody, legal custody, guardianship, and the parental relationship, which are defined as the following:

*Physical custody* means actual custody of the person in the absence of a court order granting legal custody to the physical custodian. [s. 48.02(14)] In the context of this hearing, the foster parent would be a physical custodian only, because in Wisconsin, they would not generally have legal custody.

*Legal custody* is a status created by the order of a court, which confers the right and duty to protect, train and discipline the child, and to provide food, shelter, legal services, education and *ordinary* medical and dental care, subject to the rights, duties and responsibilities of the guardian of the child and subject to any residual parental rights and responsibilities and the provisions of any court order. [s. 48.02(12)] In most cases in Wisconsin, the legal custody of a child in foster care will remain with the parent because, under our statutes, “. . . there shall be a policy of transferring custody of a child from the parent . . . only when there is no less drastic alternative. If there is no less drastic alternative for a child than transferring custody from the parent, the judge shall consider transferring custody to a relative whenever possible.” [s. 48.355(1)]

We believe that maintaining the parents' involvement, responsibility, and authority when a child is placed outside of the home is critical, if the goal is to reunify the child with the family.

*Guardianship* means a status granted by the court to a person who has the duty and authority to make important decisions in matters having a permanent effect on the life and development of the child and the duty to be concerned about the child's general welfare, including but not limited to:

- The authority to consent to marriage, enlistment in the U.S. armed forces, major medical, psychiatric and surgical treatment, and obtaining a motor vehicle operator's license.
- The authority to represent the child in legal actions and make other decisions of substantial legal significance concerning the child but not the authority to deny the child the assistance of counsel as required by this chapter.

- The right and duty of reasonable visitation of the child.
- The rights and responsibilities of legal custody except when legal custody has been vested in another person or when the child is under the supervision of the department of corrections . . . or the supervision of a county department . . . [s. 48.023]

The *parental relationship*, of course, is one in which the parent has all of the rights and responsibilities related to the care of his or her child which have not been otherwise altered by the action of a court.

Parental Authority for Participation. If parental rights have not been terminated, and if guardianship has not been inferred on another party, the parents retain the right to make medical decisions for the child.

System Authorization for Participation. Occasionally, a representative of the Wisconsin child welfare system is granted court-appointed legal custodianship or guardianship and would have the ability to approve the participation of a foster child in medical research. In these instances, it is our position that approval for such research participation should not be given solely on the basis of the child being a foster child, but rather reviewed on a case-by-case basis for medical benefits.

In other words, we are not opposed to the participation of a foster child in appropriate and beneficial medical research if:

- a foster child meets the requirements for a medical research study based on some physical, mental, emotional, or developmental condition and
- the child's parent or parents were informed and, as appropriate to their legal status, approved of their child's participation and
- the child's personal physician, therapist, or other professional recommends to the system authority that the child be involved in that research and
- children with similar or related conditions will also participate and
- the group of children and other individuals in the study include children outside of the child welfare system and
- the child was appointed an advocate with the express responsibility for determining whether participation is in the child's best interest (including ascertaining the child's position),

the representative may consider granting that authority. In Wisconsin, we believe it is our responsibility to help provide a safe, nurturing environment for the children in foster care so that they may become healthy, thriving adults. We are opposed to a foster child being involved in any such research solely because the child is a foster child. It is inappropriate to single out foster care children as a group for medical research, based simply on the fact that they are in the child welfare system.

Thank you again for your invitation to address this important issue. I wish you well and trust that legislative initiatives will be forwarded that reflect the values Wisconsin uses with regard to foster child participation in medical studies.