Health Care of Children in Foster Care: Who's Keeping Track?

Lorrie Lutz
Jane Horvath

OCTOBER 1997

Funded by the Nathan Cummings Foundation
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ACKNOWLEDGEMENTS

The authors would like to thank all the state officials who took the time to respond to our survey concerning the implementation of health passports for children in out-of-home placements. We also would like to express our deep appreciation to those individuals who provided in-depth information about specific programs, who reviewed the survey instrument, or who provided comment on early versions of this paper: Peggy Arvin, Kathy Barbell, Ellen Battistelli, Gary Malmon, Sharon Martin, Richard Matt, Pam Mindt, Jim Mowry, Wilma Rogers, Norma Ruptier, Donald Schmidt, Edward Schor, Judith Solomon, Linda Spears, Barbara Turpin, Gail Young, and Terry Williams.

Finally, we would like to thank the Nathan Cummings Foundation for their support of this paper and our program officer, Andrea Kydd, for her support and encouragement. This paper is part of a larger NASHP effort funded by the Cummings Foundation, the State Institute on Improving Health Care for Children in Foster Care. This project is a three year effort (1996 to 1999) among five participating states to improve coordination and delivery of health care screening and treatment for a group of very vulnerable Medicaid beneficiaries – children in foster care. The project involves interagency collaboration and teamwork among Medicaid and Child Welfare services at the state level in each state. The five states participating in the Cummings Institute are Alaska, California, Massachusetts, Texas, and Utah.

These states have established goals and specific projects to be accomplished during the grant period. While there is diversity in what each state intends to accomplish, there is significant commonality as well. For example, all of the demonstration states have decided to improve or implement a medical service record that resides with foster parents and the state or local government which can be accessed by care givers regardless of changes in foster home placement or changes in health care providers. All of the states are thinking through the opportunities and challenges posed by enrolling these children in Medicaid risk-based managed care systems.

Four of the demonstration states intend to develop standards of care (for screening and treatment) for these children, and three others want to focus on improving the level of understanding among foster parents and case workers about the importance of health and mental health care for children in foster care. These states also intend to improve outreach to Medicaid providers about the special needs and situations of children in foster care.

Through the Institute, state interagency teams access the advice and expertise of leaders in the field of foster care and health care. Work done for the Institute by the NASHP and project consultants will be made available to all other states as the project progresses.

The National Academy for State Health Policy ♦ 1
BACKGROUND

According to the data from the Administration on Children Youth and Families there are an estimated 600,000 children residing in foster care in our country. Each of these children enter foster care with a background of abuse or neglect sufficient to warrant being removed from their families. The children entering care present complex medical and emotional conditions that are taxing the capacity and the ability of the foster care system. Characteristics of children in Foster Care include: 1) they have been maltreated – 53% neglected, 26% physically abused, 15% sexually abused, 5% emotionally abused, 3% medically abused (US Department of Health and Human Services, Center on Abuse and Neglect, 1996), 2) they are young – infants and young children with medical complications and physical and mental limitations constitute the fastest growing groups of children residing in care (George et al, 1994), 3) they have severe disabilities – children entering out-of-home care are presenting serious and complex problems including post traumatic stress from past physical, emotional or sexual abuse, alcohol or drug exposure, HIV infection, poverty and homelessness (Halfon et al, 1993), 4) they have chronic health problems – studies have shown that almost one half the children in sample groups have had at least one chronic health problem (Schor 1982, Moffatt et al, 1985), and 5) they are in need of mental health services – studies have shown that over one-third of the children in sample groups had serious levels of psychiatric impairment (Hochstadt et al, 1987; Simms, 1989). Many children fall into more than one of these categories.

The multiple needs of children entering into out-of-home care have had a significant impact on the number of families willing to provide foster care. As the number of children needing out-of-home care increased dramatically between 1985 and 1994 (over 35% ACYF, 1996), the number of foster parents declined from 147,000 to 125,000 (National Foster Parent Association 1994). This decline is due to a number of factors including social and economic changes in our society, but it is also clearly a result of the increased demands being placed on foster families. The serious problems of children in care demand a level of commitment and time that many families in today’s society are unwilling or unable to make.

Given the gravity of the circumstances from which these children originate, the severity of their presenting medical and psychological problems and the dearth of foster parents willing to take on this level of responsibility, it seems logical that these children would be afforded access to timely and comprehensive medical, social developmental and psychological evaluation and treatment. It would also seem logical that the foster families would be provided with adequate supports and ongoing time sensitive information to ensure the children receive quality health care.

However, the research and anecdotal stories reflect a very different picture of the health care information provided to foster parents and the health care services
provided to children in care (Battistelli 1996, Klee and Halfon 1978). Health care
delivery to children in out-of-home care frequently suffers from lack of adequate
record keeping, poor communication among providers of services, lack of adequate
reimbursement for services, and lack of adequate health care supervision including
comprehensive physical and mental health screening, referral and follow up.
Although most states mandate an initial health screen occur within a set period of
time after removal from the home, (often 72 hours to five days, depending on the
state), surveys and conversations with state Child Welfare agency representatives
indicate that this timeframe is rarely met and frequently children in care do not
receive any form of initial screening. The literature is in agreement that multiple
changes in placement and concurrent changes in physicians and social workers,
together with systemic pressure to attend to the immediate safety issues rather than
the overall well-being of children in care, leads to health care for children in foster
care that is too often inconsistent and without focus.

This lack of adequate health care and subsequent lack of transferable medical records
is not due in most cases to a lack of health care coverage. The coverage Medicaid
affords children in care through the Early, Periodic, Screening Diagnosis and
Treatment (EPSDT) provisions of the Medicaid law is by most standards considered
to be a generous benefit package. This child-serving legislation allows states to
provide an array of services, which may not otherwise have been covered.

The lack of quality medical care and inconsistent documentation of services
received has not gone unnoticed. Over the past 15 years researchers, advocates and
policymakers have made both major and minor recommendations in health care
policies for children residing in out-of-home care (Schor 1981; White et al 1987;
Halfon and Klee 1987). In 1988 the Child Welfare League of America (CWLA) in
collaboration with the American Academy of Pediatrics (AAP), took this collection
of recommendations, added others and developed a comprehensive health care
policy for children in out-of-home care. One of the key aspects of this important
policy paper is its advocacy for the use of a “medical passport” to document the
health care problems and services delivered to children in out-of-home care.

In 1989, Congress, recognizing the need for the Child Welfare system to attend to the
medical backgrounds of children in care, passed legislation requiring that a foster
child’s case plan “shall include the health and education records of the minor”
(Omnibus Reconciliation Act of 1989, P.L. 101-239). The legislation reads as follows:

(1) The term “case plan” means a written document which includes at least the following:

(c) To the extent available and accessible, the health and education records of the child,
including:

(i) the names and addresses of the child’s health and educational providers;
(ii) the child’s grade level performance;
(iii) the child’s school record;
(iv) assurances that the child’s placement in foster care takes into account proximity to the school in which the child is enrolled at the time of placement;
(v) a record of the child’s immunizations;
(vi) the child’s known medical problems;
(vii) the child’s medications; and
(viii) any other relevant health and education information concerning the child determined to be appropriate by the State Agency.

This mandate, intended to promote attention to the medical needs of children in care and provide a strong federal voice regarding the need for a health care record for all children regardless of where they lived, has been elaborated upon in many states and localities to make the information more accessible to foster parents and other caregivers, and has come to be called by many the “Health Passport System”.

The purpose of this paper is to examine the success of this health passport system and to suggest concrete approaches for its improvement. The National Academy for State Health Policy (NASHP) surveyed states in the Spring of 1997 to find out the extent of implementation of health passports. The intent was to see if, and how, states were working to create systems that provided updated, readily-available, abbreviated health information to foster parents and health providers. State responses made it clear that states use a variety of terms for their systems and efforts. Further, those efforts represent a range of activity – from information kept in the case file that may or may not be complete and current, to systems of tracking, follow-up and case management. Therefore, this paper uses the terms health passport and medical passport to represent the range of activity. However, this paper clearly seeks to encourage discussion about development of viable travelling medical histories and an operational system around them which fosters greater attention to the health care needs (including mental health and developmental health) of children in out-of-home placements.

EFFORTS AT DEVELOPING MEDICAL PASSPORTS

The first efforts to develop the health passport program came out of Massachusetts in the late 1980s, resulting from a consent decree mandating that the state begin to collect health information on children who were residing in foster care. In the years since the Massachusetts lawsuit, legal advocates in other states have pursued similar actions: health care for children in out-of-home care has become the subject of an increasing number of class action suits brought against states and/or counties in an effort by groups such as the American Civil Liberties Union (ACLU) to correct system wide deficiencies (Wensten and La Fleur, 1990). As is often the case in Child Welfare, lawsuits and consent decrees have created the foundation for system change surrounding the quality, timeliness, and documentation of health care made available to a child in foster care.
Early innovations in the passport system occurred in San Diego in 1989, which began using Public Health nurses to coordinate the passport system, and to provide synthesis of obtained information with entry into a computer data base system. The San Diego system created a central computerized database of critical components of health care utilization. San Diego created a computerized health passport as one component of its effort to more fully maximize the benefits of the Medicaid EPSDT program and used Medicaid funding to co-locate Public Health nurses in the Department of Social Services. Illinois is also known for its successful paper system which is operated by counties using Public Health staff.

A program found among some early innovators is now operational in a majority of states where there is some form of system of tracking the health care of children in foster care. However, the level at which these systems function, as well as their success and utility, varies widely among the states. A recent survey conducted by the National Academy for State Health Policy (NASHP) sought to learn how many states had implemented a program, the extent of implementation, and whether the system was computerized. Of the 40 states responding, 32 had some form of Health Passport system in place (or will have by the end of 1997).1 One other state reported expected implementation in 1998. Of these 32 states, 30 have or hope to have a statewide system by the end of 1998. Eight states reported that the passport system is computerized statewide, or will be by the end of 1997. In three of the eight states, the passport is part of the SACWIS.2 Twenty other states reported an intent to incorporate passport functions in to SACWIS.

These findings are consistent with the findings of other organizations such as the Medicaid Working Group, the Concord Assabett Family and Adolescent Services, the Child Welfare League of America and the Polinsky Center, which suggest that a fairly high percentage of states have implemented some form of medical record keeping or a health passport system. The form these systems take is different among the states and many states are struggling to make their systems truly operational and effective in meeting intended goals. The problems states encounter are discussed below.

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1 The reported passport system may not be implemented statewide. See Appendix A for details.

2 Statewide Automated Child Welfare Information System.
case records and generation of abbreviated health information reports for the foster parents. The major benefits of the computerized passport system include 1) promoting quality and consistent health care for children 2) introducing an efficient method of tracking individual health data and, depending on system design, 3) providing an aggregate description of the health problems experienced by children in out-of-home care.

As David Chadwick has pointed out (1996, 1997), one of the important aspects of computerizing the health passport system is that it not simply mimic the paper system but that the data entry and tracking process be designed to maximize use of today’s computer technology. The process should provide new opportunities for innovation. A sophisticated, computerized medical passport system can enable Child Welfare and community leaders to do meaningful planning, describe needs and identify gaps in service delivery, and coordinate the provision of services at the local level. It can also be used as an education and research tool in lobbying the legislature about the requirements of a fully integrated system of care at the local level.

According to information compiled from the recent NASHP survey, the states of Iowa, Massachusetts, Oklahoma, Oregon, Vermont, Washington, Texas, and Utah have already computerized some aspects their health passport system statewide (or will computerize this year). California and Missouri reported computerized passport systems on less than a statewide basis. Many other states indicated that they intend to integrate the health passport function into SACWIS.

Some states are creating or have created on-line linkages between Child Welfare and Medicaid to promote ready access by Child Welfare case workers to Medicaid eligibility and/or service histories. It is not clear that health care (or other foster care providers) can have access to the Medicaid service information because of limits on the release of client-specific Medicaid information as specified in federal Medicaid law. Some states allow on-line access to eligibility information for Child Welfare workers. On-line, real time eligibility information available to Medicaid providers has been a feature of some state Medicaid programs for a number of years and is consistent with federal limitations concerning disclosure. There are also examples of states where a medical utilization history (selected items) is sought from Medicaid on new children entering state custody in order to initiate a health passport. In Massachusetts, the system anticipated to be operational in the Fall of 1997 will provide a template for Medicaid and Child Welfare system integration. In their planned system, once a case is opened to the Department of Social Services the name of the child is immediately sent through the computer network to the Medicaid unit. If the child was ever known to the Medicaid system the name, address and phone number of the primary care doctor and any other critical medical information the Medicaid unit may have will be entered into the child’s health passport. The social workers and foster parents will have immediate access to
information that previously might have taken weeks to discover. Massachusetts Medicaid is considering various options that may enable them to provide claims data to the health passport system during a semi-annual run of Medicaid claims. It has not been determined yet whether the system will be feasible.

In Connecticut, the quasi-governmental Children’s Health Council is working with Medicaid-contracting managed care organizations to analyze access to well child preventive services. In addition to generating reports for the Medicaid agency profiling EPSDT service use of the general child-enrollee population, the Council is specifically generating profiles of enrollees who are children in state custody for the state Child Welfare agency. The individual profiles relate to children who have not received timely screening services and the aggregate reports detail population-based ‘compliance’ with EPSDT screening targets. While the Connecticut model does not generate a specific health passport, it is an interesting example of using data from sources outside the Child Welfare agency to create aggregate profiles of the foster care population in relation to preventive well-child services and individualized reports on timeliness of services. The Connecticut program has addressed the confidentiality issue (the MCO information is merged with Medicaid eligibility files) through a contractual relationship with the State wherein the Council supports proper administration of the State Medicaid plan by ensuring that EPSDT requirements are being met.

Utah Child Welfare and community health agencies are working with the largest single provider of health care services to children in foster care, (the State university), to create a database of services to children in out-of-home placements. The hope is that over time a population-based profile of these children can be created. It may also lay the foundation for a solid, accurate health passport system to the extent that the university clinic is the sole provider of health care for the children it sees. It could also lay the basis for a successful passport system to the extent that other health providers can be networked into the university system. This system also does not rely on data in the possession of the state Medicaid agency.

Another approach is being tested in the states of Wyoming, Nevada, and North Dakota. Under the leadership of the Western Governors Association, these states are embarking in the Fall of 1997 on a unique model of computerized passports integrated with other essential information concerning the child’s eligibility for various state and federal programs and services. System planners, recognizing that many foster parents leave the passport at home when going to the physician’s office, wanted the passport to be in a format that caused it to be indispensable to, and well utilized by, the foster parent. The proposed solution is to create a single magnetic read/write card that contains the health passport information and eligibility (and other relevant information) for a wide variety of public agency services including TANF, Food Stamps, WIC, Head Start, and Medicaid. The card will house a computer chip containing 10-12 pages of the child’s most recent medical record and
the most critical aspects of the child’s medical history. The computer chip, based on smart card technology, enables the provider to both read and write in the medical record. If the provider writes to the card, there is no need for obtaining Medicaid claims data, although Medicaid claims data could be used to validate the information on the card.

While the authors of this innovative approach are guarded in their optimism, this technology has great potential. It would promote ease of access by physicians or other health care providers to the medical history of the child, allow for the immediate updating of the file, allow for child care providers and school officials to have immediate access to immunization records and eliminate the responsibility of the overburdened social worker and foster parent in assuring that the medical passport was completed. The system designed has resulted in questions or concerns about confidentiality (discussed later).

DESIGNING A SUCCESSFUL SYSTEM

OPERATIONAL ISSUES
In thinking through optimal design for a passport or other system of collecting and disseminating health information of children in out-of-home care, it is important to note that there are a number of outstanding issues in terms of the best approach to designing a successful passport system. States have chosen different approaches for each component of their passport system, and each component can be important in affecting the success or effectiveness of the program. But, because of the variety across all the variable components, it is difficult to compare one state program to another. Some of these variables include the following.

- Designating a responsible party for initial creation and then ongoing upkeep of any particular record: nurses, caseworkers, foster parents, doctors.
- Organizing the update of the record: the central file is held with the foster parent, the central file is held in a state or county office with updates mailed to foster parents, the doctor mails in an encounter form, the doctor adds directly to a health passport.
- Specifying the contents of the passport or record: abbreviated information about most recent provider, significant health diagnoses, immunizations; or add dental, mental health, and prescription drugs and an extensive medical history so that the passport approaches a medical record.
- Determining the sources for the information: if Medicaid claims data or MCO encounter data is to be used, there may be limitations of that data in terms of accuracy, scope, and timeliness relative to the information desired in the passport.
- Determining whether the system is paper or electronic.
- The periodicity with which information is passed to foster parents: whether central file is periodically sent to foster parent or whether new information is
provided only upon placement.

After initial implementation, many states struggle with ongoing application of the medical passport rules and policies. Conversations with a subset of the states responding to the NASHP survey highlighted a fairly consistent problem with the functionality of the health passport system. State representatives indicated that generally only 15-20% of the case files of children in foster care actually contain all the health information that should be included. They describe problems associated with misplacing the paper passport, significant problems updating the information in a timely and efficient manner, that the information is not available in aggregate form to monitor the overall health status of children on the caseloads, and lastly, that the information included in the health passport is not user friendly—they are usually written in medical language.

However, state officials who have worked with health passports, whether paper or electronic, have identified a variety of problems or barriers to the effective operation of their systems. Taken together, there is sound advice in this collection of concerns in how to plan and operate a system that has the potential to be successful.

**Beginning the Process of Developing a Health Passport System**

Where should a state begin? Although the development of a medical passport system may appear overwhelming, states that have had success in their efforts offer the following strategies for successful implementation.

*Develop Underlying Principles and Goals*

Establishing a guiding set of principles prior to the development of a health passport program may be valuable and help focus the discussions during the more complex phases of the implementation process. State officials should identify why a system of updated information on key components of health care for children in out-of-home placement is important, what such a system should accomplish, and what the legal parameters of the system should be.

Washington State has outlined a set of Guiding Principles, Philosophy and Legal Requirements that may be of value to other states and localities as they consider developing a medical passport system (see boxes). In general, the system should be designed to account for existing available resources – both financial and human. For example, it may not be appropriate to build on a model such as San Diego (using Public Health nurses to coordinate the system, verify, synthesize, and enter the information into the system) if expanded funding opportunities are unlikely.
The Values Include:

1. All children have the right to have a record of their own developmental, social, health and educational historical information.
2. Health and education data is essential information for the development of optimal case plans for children.
3. Child Welfare staff have a responsibility to make sure that the information is collected, maintained, and utilized:
   - by social workers
   - by foster parents
   - by biological parents
   - by adoptive parents
   - by all other caretakers
4. Creation and maintenance of developmental, social, health and educational information for children in out-of-home care must be collaborative effort between child welfare agencies and the various community service system – private agencies, families and providers.
5. The system must be:
   - automated and connected with other systems
   - streamlined, with a “relational” data base
   - structured to minimize the workload impact on the social worker


The system should also be predicated on existing state laws and regulations governing the disclosure of information on Child Welfare cases, and respecting any restriction/limitations on the use of information generated from Medicaid.

<table>
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<th>The Legal/Regulatory Requirements Include:</th>
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<tr>
<td>1. Title IV-B as amended by PL 101-239</td>
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<td>2. Indian Child Welfare Act requirements including use and involvement of Indian Health Services and traditional Indian therapy</td>
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<tr>
<td>3. Educational laws in regard to immunization requirements as a precondition of attendance</td>
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<tr>
<td>4. Early Periodic Screening, Diagnoses &amp; Treatment (EPSDT) requirements</td>
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<tr>
<td>5. Other supporting (but not required) initiatives:</td>
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<td>- Public Health Improvement Plan</td>
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<td>- “Healthy People 2000” goals</td>
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<tr>
<td>- Family Policy Council guiding principals</td>
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<td>- SACWIS requirements</td>
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The system should be designed to tap into all reasonably available sources of information among health care providers and stakeholders (such as foster care service providers, parents, and mental health providers). To the extent possible, data entered should be verifiable and verified, if only on a sample basis, to check on the completeness on the record with respect to key information such as the most recent health care provider, immunizations, current HMO enrollment, or other aspects. Child Welfare could work with MCH programs or other state health
systems that maintain immunization or lead screening tracking systems to collect or validate existing data. Child Welfare could also consider tapping into any existing immunization or lead screening registries that exist at the state or local level as a source of information for the passport.

If Medicaid claims or encounter data is to be used, it is important to acknowledge the limitations of these sources and plan accordingly. For example, claims/encounter data may not include all the conditions affecting the child. Further, claims/encounter data may not identify a specific attending provider within a group practice or clinic. Timeliness of the data may also be an issue, particularly claims data, where a claim may be filed considerably after a service is provided (either because the claim was not accepted initially, or because the provider delayed filing, or both). A claim may be filed considerably after a service is provided (either because the claim was not accepted initially, or because the provider delayed filing, or both). With encounter data, the reporting period from the MCO to the state may create substantial time lags.

The Broad System Requirements Include:

1. There must be a designated staff in each region responsible for the following:
   - Collecting, collating and entering the information
   - Public Health Nurses must be available to interpret the information, provide assessments, teach, consult and facilitate appropriate follow up referrals

2. There must be a relationship with state and community partners including
   - Education
   - Social Services
   - Public Health
   - Local Public Health
   - Community Providers

3. The system should interconnect to other systems including
   - Medical Assistance
   - Child Welfare Information System
   - Public Health databases


Bring Various Expertise to Bear on the Design
Officials from the Child Welfare, Public Health/Maternal and Child Health, and Medicaid systems should come together to answer the following questions:

- Who will collect and record the information?
- When is it useful to use clerical staff?
- What information should be collected, summarized, and referenced to another source?
- Should the system be electronic?
- How will the foster parents gain access to the information and how frequently?
• How will the provider access the health information?
• How does the caseworker ensure that the information is included in the child’s permanent file?
• How will the system work for children who move many times?
• How does/should the passport interface with the case plan?

Plan for Difficulties
Representatives from states working on the development of medical passport systems suggest that even with the best intentions, the process of designing and implementing a medical passport program can encounter major operational obstacles. They have provided the following proactive suggestions that can help overcome operational barriers and facilitate success.

• Emphasize the need for support at the top policy levels and the willingness to invest the resources and time to make the system work efficiently.

• Facilitate discussions addressing the issue of confidentiality and creating consensus around what and how information is to be shared (discussed below).

• Create flow charts demonstrating how key players will gain access to the information they require.

• Address the complexities involved in the constant movement of children from one home to another and (if necessary) the lack of identification numbers that allow for the easy tracking of children. Placement decisions should include consideration for continuity of health care treatment for the child.

• Think through the implication and benefits/drawbacks of assigning responsibility for passport creation and upkeep to particular parties.

• Develop strategies to ensure information being entered into the database is timely and accurate. States could consider running data matches with Medicaid or other state child health tracking system to see if passport record is complete.

• Ensure that information is usable. Creation of a medical record as a health passport may imply collecting provider-generated records and documents into a folder given to each new foster family. This type of information may not be readable (legibility or language), nor arranged in a way that is usable. States should give serious consideration to creating abbreviated summary documents rather than passing around original source material and expecting parents and providers to make sense of it. States should also consider...
accessing Medicaid claims histories for selected items if confidentiality issues can be addressed.

- Work with Title V MCH programs and Medicaid to outreach to health care providers to create expectations around the health passport system. Depending on the passport system design, providers could be encouraged to ask for passport information from foster parents (or other responsible party). Where the system relies on the health professional to report information back to Child Welfare, letters of acknowledgment could be sent when the appropriate paperwork is filed.

- Design and implement a training and educational program that will focus the attention of social workers on ensuring that the existing health passport information and appropriate medical forms are in the child’s file and brought to the foster parent when the child is placed.

- Determine if an evaluation strategy/process is desirable. Evaluation could include checking on data validity or the usefulness of the information. In addition to data matching and record review, surveys of case workers, medical providers, and foster care providers and parents should be considered.

**Significant Design Issues**

There are two extremely significant issues that states must address in the development or redesign of their passport systems: client confidentiality and responsibility for passport creation and updating. There are state and federal rules and regulations, concerning client confidentiality in both Child Welfare and Medicaid. The Medicaid issues will only need to be addressed to the extent that the passport system relies on Medicaid information. The second issue, of who is responsible, can be the second critical determinant of whether the program will be effective. Each issue is addressed below.

*Client Confidentiality in Child Welfare and Medicaid*

In every state, information gathered during the course of a child protection investigation is held to a fairly high level of confidentiality. Hospitals, public health staff, social workers and community providers have been trained in the importance of not sharing this information without a court order or some form of legal permission. Because medical data and information gathered during a child protection investigation is often intertwined, this mandate for confidentiality may cause confusion and create barriers to effective case planning and information
sharing. As states work to design an integrated system of care where information sharing is the cornerstone of successful case planning, treatment, and documentation, confidentiality laws and rules are often very problematic.

In order to overcome these barriers, Child Welfare leaders should examine the origin of the confidentiality legislation – its purpose and its relevance in today’s world of technology – and determine how the statute can be improved and changed to enhance services to children and their families. There are methods and standards which can be employed to ensure that the rights of privacy are protected and still ensure that information is accessible which is critical to comprehensive case planning and treatment. Physicians and social workers would be well served to find ways to share critical medical information that will best serve the child.

In January 1996, the Concord-Assabet Family and Adolescent Services program sponsored a teleconference on the medical passport system. States from throughout the nation including Alaska, California, Idaho, Oregon, and Washington participated. The following recommendations to begin to address the issue of confidentiality grew out of that discussion:

- Gain consensus from a large body of stakeholders regarding the importance of timely information sharing. Include judges and other members of the legal community in the process.

- Ask for the assistance of this group in designing a consent form which has both an educational and functional purpose. It was recommended that the consent form outline the benefit of the data for the child and have a place on the form for the signature of the representative of the child.

- When a child enters the system, take the time to educate the parents/caregiver about the importance and need for information to be shared across agencies and between providers.

- Set up procedures which make it very clear that a representative of the child, sanctioned by the court, can review the data at any time and if the data is perceived to be inaccurate this representative can challenge the information in a formal process. Make it also clear that when hearing the challenge, officials will make the decision based on what is in the best interest of the child.

- Review the statutes which guide information sharing in the state and make recommendations to the Child Welfare agency regarding changes which should occur to eliminate the barriers for effective and efficient information sharing.

A multi-state approach to the issue of confidentiality is also currently underway. The Governors of North Dakota, Wyoming, and Nevada brought a diverse set of stakeholders to the table to identify the concerns which arise among advocates and practitioners surrounding confidentiality issues in the implementation of an electronic health passport system on a read/write magnetic card. This group has
been charged with finding solutions in a manner which respects rights of the child and his/her family and also allows professionals to work together efficiently.

As for Medicaid, there are ways of constructing the data relationship between Child Welfare and Medicaid so as to comply with federal law, which holds that client-specific data can be shared only for purposes of administering the state Medicaid plan. For example, states could explore provision of EPSDT data for purposes of improving the rate of children receiving required EPSDT screening and treatment services as specified in federal law and regulation. Some states, such as Iowa, already use Medicaid EPSDT data as the basis for creating a medical history of a child when a case is opened.

**Assigning Responsibility**

In follow-up conversations with states responding to the NASHP survey, numerous states suggest that the issue of who should be responsible for ensuring that the medical passport is completed is significant to the overall success of its implementation. In those states where the social worker is solely responsible for implementation the results are less than impressive. Lack of understanding regarding the core relationships between health, education, and social supports is exacerbated by caseloads that in nearly all states exceed every standard written (CWLA 1996). The tremendous pressures born by social workers to meet the complex needs of children and families creates a crisis response mentality. When the lives of children are on the line, the environment quickly shifts from being planful and proactive to reactive and narrowly focused. “This environment does not allow for the expenditure of the time required to ensure that the host of needs and concerns of children and families are met. The mentality becomes one of ensuring that the child is safe expecting the rest of the system to ensure that the child has access to health care” (Spears, 1997).

When the foster parents are solely responsible, the situation is equally challenging. Foster parents are relied upon to take children to and from a host of appointments including medical appointments. Foster parents who see medical care as a priority due to their own orientation to parenting, will try to make certain that children in their care receive consistent medical attention and that the care is documented in the child’s case file. However, not all foster parents recruited view medical care as a priority. When foster parents are caring for many children, (in many states up to six excluding their own), and several of those children are toddlers or infants, the trip to the doctors office can be very time consuming and complicated. When medical appointments do occur, the foster parent may not have the time or energy to underscore the importance of the physician filling out the medical passport paperwork.

It comes as no surprise that the need to ensure that each child in the system has a comprehensive medical record is too large a task for any single aspect of the system.
In areas of the country, such as Chicago, Illinois; San Diego County, California; Onondaga County, New York; certain regions of Massachusetts; and Seattle, Washington, where there has been a concerted effort to use a multi-disciplinary approach to gathering medical information and ensuring ongoing access to health care, the rate of case files containing medical records is significantly improved (45-60%). In Massachusetts although not every case is brought before the multi-disciplinary teams, those that are provide an opportunity for social workers, nurses, physicians, the clergy, attorneys, biological and foster parents to discuss the many and diverse needs of the child. “We still struggle to get 100% of the children in care timely medical and dental services – however, the multi-disciplinary team has opened up the thinking of our workers to a whole multi-disciplinary approach and way of thinking which includes the importance of medical care, early intervention and behavioral health services in the life of a child” (Judy Abrahams, Area Director of Massachusetts DSS Framingham Office).

Additionally, Child Welfare agency leaders may need to consider following the example of counties such as San Diego and create a first layer of out-of-home care, called the emergency receiving home, where children go upon removal from their homes while they await a decision regarding placement in an appropriate setting. In these emergency receiving homes the child is provided a brief and limited health screen for the presence of infectious diseases, documentation of abuse, and discovery of obvious health conditions that would affect placement. The information obtained during this health assessment is entered into the health passport data base. If the court legally detains a child, and social workers obtain a written consent for release of information, passport clerks are assigned the responsibility requesting information from all sources provided by foster and biological caregivers. Information such as the child’s birth hospital, primary care physician, dentist, mental health provider, school last attended, immunization history, history of health problems, and hospitalizations are all documented. Health Passport clerks also ask for a written release of information. Once this release is received from the parents or legal guardians, the clerks mail computer generated requests for information to facilities and or providers named by the parents. If the parent does not have a phone or cannot be located, the passport clerk has the responsibility to gather the information from current caregivers. This model assigns the responsibility of gathering the information to someone other than the foster parent or the social worker and ensures a timely and efficient method of information gathering.

Also, an increasing number of states are employing public health nurses in the various offices of social services throughout the state to review health information and provide consultation to foster parents, social workers, and health care providers. This model formalizes the relationship between medical care and social supports at the service level which assists the social worker to develop an understanding of the individual child’s health issues and address them within the
case plan. Some states and localities access Medicaid funding to finance part of the Public Health nurse function as assisting in proper administration of the state Medicaid plan and assuring compliance with the goals of EPSDT.

States such as New Hampshire, Connecticut and Illinois, who invite biological and foster parents to multi-discipline team reviews, find that both sets of parents report greater understanding and awareness of the importance of meeting the health care needs of the child. Finally, several states including Ohio, Oklahoma, Mississippi, and New Hampshire have designed a comprehensive training program for foster parents which emphasizes the importance of health and medical documentation, and relationships between the medical and social service community.

RELATIONSHIP TO OTHER SYSTEMS
In addition to the pragmatics of implementing the system, there are a variety of ‘mega-system’ issues that should be addressed. State officials need to think about how to change the culture of some of the key systems that ultimately come to bear on the health of child in out-of-home placement: schools of social work and schools of medical education.

Affecting Graduate Professional Education
One of the key reasons for the poor success of the medical passport program is the fundamental lack of understanding regarding a broad definition of health and well-being at the social worker level. This gap in understanding can be tracked back to our university systems which do a poor job in most cases of designing curriculum that underscores the interconnectedness of health, poverty, education, crime and family functioning. Social workers come out of higher education systems well versed in the history and philosophical orientation to the field of social work, but are for the most part, completely unfamiliar with the health care delivery system of our country or the problems the impoverished have in accessing appropriate medical services.

The importance of health care (broadly defined to include health, mental health, and developmental health) in providing for the well-being of all children, particularly neglected or abused children, needs to be introduced into the academic curriculum of social workers within universities across the country. Child Welfare commissioners need to be in contact with their state university systems to discuss how health care issues are addressed in that curriculum and to press for change.

Conversely, a more comprehensive curriculum of social welfare issues in medical schools and family and pediatric residency programs is also needed. Child Welfare commissioners in tandem with Medicaid directors should invest time to help the state’s medical society as well as family and pediatric residency program directors understand Child Welfare, foster care, and the exceptional health needs of children served in these systems.
Cross-training at this critical juncture in the learning process of these professionals can impress the importance of assessing children’s needs with a very wide lens and providing services which encompass a multitude of disciplines.

Continuing Education of the Provider Community
Child Welfare leaders need to work with the medical community of the state or jurisdiction to ensure that physicians, nurses, and nurse practitioners are well versed in the Child Welfare system of the state. Education on reporting requirements, commonly offered by Child Welfare staff to the medical community needs to be expanded to include: 1) information on the life of a child in care including the frequency of moves, 2) the fundamental importance of timely and user friendly medical documentation in the case file, 3) the most common medical problems presented by children in care and how those percentages compare to the general population of children in the state, and 4) who reads the case file and for what purposes. Child Welfare leaders need to make concerted efforts to speak the language of the medical community and impress upon the members their role in ensuring the well being of children in the Child Welfare system. Child Welfare should consider using Public Health/MCH and Medicaid agencies to reinforce the message and assist in outreach.

State Agency Coordination and Collaboration
Even with the efforts that have taken place in Child Welfare since the passage of P.L. 96-272, there continues to be a fragmented approach to service delivery. This lack of integrated case planning does not allow for the ease of information flow critical in the design and development of an effective health passport system. Medical, mental health and educational issues are not addressed in a systematic fashion in case plan development, and information is not shared easily across disciplines. And as of yet, there is not a common language, common information systems, or common values between child-serving systems – making the sharing of information quite complicated.

Child Welfare, Medicaid, Health, and Education officials among others, need to begin (and then institutionalize) the concept of an interagency, multi-disciplinary approach to serving children in out-of-home care. Child Welfare can take the lead in working with sister agencies to educate about the very special needs and circumstances of children in out-of-home placement. Multi-agency teams can be created to discuss the role of each agency in serving these children and coordinating delivery of tracking of services – agencies to consider pulling together in a roundtable include education, MCH, Medicaid, mental health, mental retardation/developmental disabilities. The courts need to be brought into the process as well. States agencies can consider reaching out even further to community-based providers once the agencies themselves have come together, or the different agencies could independently collect input from those community
providers with whom they work.

MEDICAL PASSPORTS UNDER MEDICAID MANAGED CARE

This paper has so far examined issues of creating a health passport system where the locus of responsibility is the Child Welfare system for locating, collecting, and organizing the basic health information for children in out-of-home care. However, the growing movement of Medicaid programs into risk-based, capitated contracting for a full range of health (and some social) services may present opportunities to redesign health passport information programs. (In fact, re-design may be necessary if any aspect of the existing passport system relies on Medicaid fee-for-service claims data, which may disappear as this group is moved into risk-based arrangements.)

The NASHP survey of passport implementation did not delve into this issue of implementation in a Medicaid managed care environment so there is no survey-based information about state activity in this area. However, there is some known anecdotal information and probably much more that states are already considering.

At least one state, New Jersey, is requiring their health plan contractors to accommodate the need to transfer providers and medical records quickly when the placement of child in foster care changes. The State Medicaid agency has made it a matter of contractual agreement between health plans and the agency. In Connecticut, as mentioned previously, the Medicaid contracting health plans provide data on child service utilization from which is produced a report on use of EPSDT screening services by children in state custody. This model has potential for many other states.

It seems that there is the possibility to improve the record keeping and reporting on the health care of children in foster care through organized delivery systems under Medicaid managed care. These contractors have, or are developing, complex data reporting systems to accommodate encounter data requirements of many state Medicaid agencies. (Thirty-two reported requiring encounter data for all services and four required it for some services in 1996.) Using the centralized data systems of these MCOs, it may no longer be incumbent on individual foster parents or treating physicians to separately report to Child Welfare, depending on the information the state has chosen to collect.

While the basic Medicaid managed care model will likely work well for basic health passport information – current doctor, immunizations received, chronic conditions – it may work less well when 1) there are multiple managed care systems in which the child is enrolled (mental health and physical health), and 2) when the passport system intends to collect more than basic health information. Coordination by the
Child Welfare (or other) agency would still be necessary to make the system function. However, given the low rates of passport completion and update, the new Medicaid system may offer great potential, even if not inclusive of all services a child in foster care may receive. Medicaid and Child Welfare agencies should be mindful of the potential to improve health information and service delivery as Medicaid managed care moves to encompass the child in out-of-home placement.

CONCLUSION

The NASHP survey of state activity around health passports shows generally that there is greater effort and attention paid to documenting the health care of children in foster care than was commonly thought to be the case. The success of these efforts in accomplishing the immediate goal of tracking and monitoring services is not assured. There are multiple, outstanding barriers that need to be addressed in order to make many of the existing systems truly effective. Lack of accomplishment in the first goal makes it less certain that the ultimate goal of improving the health care and health status of children in foster care is being achieved.

States are well aware of the shortcomings of their systems but crafting the solutions can be difficult. It would seem that the most likely option for improvement and system success in tracking health care would be to rely more on Medicaid information to initialize and possibly update the health file of children in foster care. To that end, a number of states are working to address the barriers through multi-disciplinary and interagency approaches and/or the effective use of available technology. Medicaid claims data is not likely to be the whole answer given its limitations, but it may represent a valuable start on which states can build.

Even where a state may not undertake to specifically improve the operation of a health passport system, changes in the funding and contract structure of the state Child Welfare program may lead to promising change. Discussions occurring at the state level about moving Child Welfare systems into more “managed” systems of care have engendered new discussion about the relationships between the health care and child welfare. The more that Child Welfare systems are challenged to integrate systems of care through private contracts at the local level, the more that health, safety, and well-being are under consideration as part of a fully integrated system of care.

Changes to the Medicaid system as it relates to coverage of children in foster care also can have a positive impact on the health care of these children even when improving the operation of the health passport system is not the prime goal. Discussions about including the foster care caseload into new systems of Medicaid managed care has had the positive effect in some states of both 1) focusing the attention of Child Welfare agencies on issues of health care and 2) focusing the
attention of Medicaid agencies on the issues of children in foster care.

Even with new structures, the process of improving health care tracking and service delivery will not be automatic nor will it be easy to accomplish. However, changes in either system, Child Welfare or Medicaid, that result in new structures accompanied by new responsibility and accountability will have the potential to improve the health care provided to children in foster care.
APPENDIX A
Survey Results
<table>
<thead>
<tr>
<th>State</th>
<th>HPs are Administered at what Level (County or State)</th>
<th>HP system policy decisions are made at what level (County or State)</th>
<th>Number of Counties in State</th>
<th>Number of Counties HP has been Implemented</th>
<th>Implementation across state was completed or is expected by</th>
<th>The HP system is currently computerized</th>
<th>Does SACWIS incorporate the HP function/purpose</th>
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The National Academy for State Health Policy
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<th>HP system policy decisions are made at what level (County or State)</th>
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<th># of Counties HP has been Implemented</th>
<th>Implementation across state was completed or is expected by</th>
<th>The HP system is currently computerized</th>
<th>Does SACWIS incorporate the HP function/purpose</th>
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40 responses
NR= No Response given by state NA=Not Applicable per state

Person responding to survey is responsible for oversight of Health Passport System: 18 states
CA, KY, ME, MI, MS, MO, NE, NH, OK, OH, OR, PA, SC, SD, TN, UT, VT, WA.

Person responding is NOT responsible for oversight of Health Passport System: 18 states
AK, AZ, AR, AL, CT, CO, FL, GA, IA, IL, IN, KS, MA, NJ, NY, RI, WV, WY.

No one is responsible: 2 states
DE, ID.

Did not specify who was responsible: 2 states
MN, TX.

1. AK responded with: None of your choices on the survey seem applicable. We are piloting the health passport in Anchorage, our largest community. AK does not have counties. We are using the San Diego model for now. Hope to include in our SACWIS system in Phase 2, but don’t know whether that will occur.

2. 4 counties definitely, total number unknown. Some counties have implemented, but system is not truly functional.
3. Included in CSW/CMS system.
4. Delaware does not use the health passport system.
5. Idaho does not use the health passport system.
6. Iowa does not use the health passport system. Instead the state uses Medicaid EPSDT screening and treatment claims information to build the case file when a case is opened. Then DHS updates the information directly from providers.
7. This is the earliest reference found in the Kansas statute requiring health records for foster children.
8. Health information was computerized a few years ago, but is inconsistently applied/utilized.
10. Implementation planned for 8/97.
11. NH is still in the process of developing the health passport. There is a collaborative between public and private non-profit agencies to build a comprehensive medical component to the state’s foster care program. The passport in only one component.
12. Social Service Districts (SSDs).
13. As of effective date of Federal Legislation.
14. Texas keeps paper files for all health information. Caseworkers will be required to use SACWIS to record annual medical exams and bi-annual dental cleanings but other information will remain on paper.
15. SACWIS will be used to document annual physicals and dental cleanings.

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16. New computer system currently being implemented.

17. Partly, identification of new custody entrants for DOH done by computer.

18. VT does not use/do SACWIS.

19. Thinking of piloting a project in 3 counties.

20. In the planning stage for all health passport issues.
APPENDIX B
Survey Instrument
Survey on the Status of Implementation:
Health Passports for Children in Out-of-Home Placements

The purpose of this survey is to gather baseline information about the status of state or local
implementation of health passports/traveling medical records, as required by federal law, for
children in out-of-home placements. Please take a moment to answer the following questions. We
will send you a copy of the report summarizing the survey results.

Respondent’s Name: ____________________________ State: ________
Respondent’s Agency: _________________________ Respondent’s Phone: ______________________

Is respondent responsible for oversight of the health passport system?
☐ yes  ☐ or  ☐ no

If no, who is responsible?
Name: ____________________________
Agency: ____________________________ Phone: ____________________________

1) In your state,
Is the health passport system administered at the ☐ county or ☐ state level?

and
Are health passport system policy decisions made at the ☐ county or ☐ state level?

2) Number of counties in your state? ________

3) Number of counties where the health passport system has been implemented? ________

4) Is implementation across the state expected (or completed)?
☐ yes, implementation across the state is expected by
   __________(mo)/__________ (yr), or
☐ yes, implementation across the state was completed by
   __________(mo)/__________ (yr), or
☐ no, implementation across the state is not expected, or
☐ do not know if implementation across the state will occur.

5) The health passport system is currently computerized?
☐ yes, throughout state, or
☐ yes, in a majority of counties that have a passport system, or
☐ yes, in a minority of counties that have a passport system, or
☐ no

6) Does the SACWIS* incorporate the health passport function/purpose?
☐ yes, it does now/will incorporate function/purpose or
☐ no, or
☐ do not know if function/purpose is/will be incorporated.

Thank you for your time.

Please return to Cynthia Pernice by April 30, 1997 at:
The National Academy for State Health Policy
50 Monument Square, Suite 502, Portland, ME 04101
Ph: (207)874-6524 Fax:(207)874-6527

*Statewide Automated Child Welfare Information System