Family Perspectives on Integrated Child Health Information Systems

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The perspectives of families, and especially parents of children with special health care needs, need to be better understood by the government agencies, health care providers, associations, and information systems vendors that are integrating child health information systems. To date, research on children with special health care needs has not included the perspectives of parents on integrated child health information systems. Interviews were conducted with a limited number of parents of children with special health care needs and a young adult with special health care needs about their perspectives on integrated health information systems needs. The interviews revealed common themes: (1) parents have experienced the benefits of information technology for health care purposes, (2) parents believe integrated health information systems could help to coordinate their children's health care, (3) parents believe information technology can help improve accuracy and timeliness of information, (4) parents of children with special health care needs believe their children's health information should be available to those who need it, but safeguards must be in place, (5) parents believe health information systems can improve health care, but it is not the highest priority health care issue for them, and (6) parents believe that their involvement in issues related to children with special health care needs, including information technology, is critical. Parents of children with special health care needs hold strong opinions about their children's health care, including health information systems. Parents need to be central to discussions about development of integrated child health information systems if we are to develop information systems that serve the needs of children with special health care needs and their families.

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More than 12% of the nation's children have special health care needs. As federal agencies, states, provider organizations, hospitals, and information systems vendors begin to integrate information systems in order to improve the quality of health care, it is important to gain better understanding of the perspectives of these key stakeholders on their needs with respect to health care, health information, and integrated health information systems, specifically.

Two recent surveys have detailed parents' perceptions of the health care provided to children with special health care needs. The National Survey of Children with Special Health Care Needs, developed and launched by the Maternal Child Health Bureau and the National Center for Health Statistics over a 3-year period beginning in 1999, was a comprehensive survey to provide information about the prevalence of children with special health care needs and determine the impact and status of the health care system on these children and their families.[1] A 1998–2000 survey, What Do Families Say About Health Care for Children with Special Health Care Needs, by Family Partners, a collaborative project of Family Voices and Brandeis University, was conducted to provide statistical and qualitative information about the ability of the health care financing

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and delivery systems to meet the needs of families of children with special health care needs.[2]

These surveys uncovered important perceptions of parents about health care issues that are extremely relevant to children with special health care needs, such as the medical home, family-centered care, coordination of care, access to health care, and insurance. But they included no questions about parents' perceptions of the impact that information systems specifically have had or could have on health care provided to children with special health care needs.

As health information technology receives increasing visibility and support at the national levels, through such initiatives as the National Health Information Infrastructure[3] and President Bush's plan to ensure that most Americans have electronic health records within the next 10 years,[4] it is important to gain greater understanding about parents' perspectives on health information technology. For children with special health care needs, who have frequent interaction with health care providers and the health care system, such proposals may have the greatest impact, and thus their views must be given special consideration.

Interviews With Parents of Children With Special Health Care Needs

To gain basic insight to the perspectives of parents of children with special health care needs regarding health information technology and integrated health information systems specifically, a small number of individuals were interviewed who have personal experience with children's special health care needs and who are familiar with the concept of "integrated child health information systems"—systems that "provide a range of information to the end-user in a simple yet comprehensive format so that he/she can readily take all appropriate actions."[5] The interviews were conducted by telephone over a 1-week period in April 2004. Interviewees were provided 10 open-ended questions designed to elicit information about the child's health situation that would provide context for answers to other questions, the health information challenges they had experienced, and their opinions about health information and integrated health information systems in the medical care system. Interviews averaged 45 minutes in length (see Table 1).

The interviewees, who reside in 4 different states, included:

- Parent A, mother of a child with a rare genetic disorder and member of a state newborn screening advisory committee
- Parent B, mother of a child with a muscular disorder and asthma, and executive director of an advocacy group for families of children with special health care needs
- Parent C, mother of a child with a genetic disorder, and parent consultant to a state newborn screening program
- Z, a 19-year-old woman with sickle cell disease who had spoken at a meeting of state genetics planning grantees

The common themes that emerged from these interviews are discussed in the following subsections (see Table 2).

TABLE 1 Interview questions

1. Tell me about your child and his/her health care situation.
2. What information challenges have you encountered as a parent of a child (child/young adult with special health care needs) with special health care needs?
3. How do you think that an integrated information system would have made that outcome different?
4. From your perspective, who should have access to your child's information?
5. Has control over access to information ever been an issue?
6. In your ultimate vision for an integrated health information system, what kinds of information would be available?
7. Does the need for integration of health information diminish as a child gets older?
8. In relationship to other challenges faced by parents of children with special health care needs, how important is integration of health information systems? Please rate 1–5, with 1 being lowest.
9. What can parents do to advocate for integrated child health information systems?
10. Has awareness of the advantages that integration of health information systems can provide increased? What needs to happen to make integrated child health information systems a reality for all children with special health care needs?

TABLE 2 Common interview themes

1. Parents have experienced the benefits of information technology for health care purposes.
2. Parents believe integrated health information systems could help to coordinate their children's health care.
3. Parents believe information technology can help improve accuracy and timeliness of information.
4. Parents of children with special health care needs believe health information should be available to those who need it, but safeguards must be in place.
5. Parents believe health information systems can improve health care, but it is not the highest priority health care issue for them.
6. Parents believe that their involvement in issues related to children with special health care needs, including information technology, is critical.

Parents have experienced the benefits of information technology for health care purposes

Each of the interviewees frequently use information technology to find information about health care, including pregnancy, child development, diseases, disorders, and disabilities, and to communicate with providers and other families. None have received any direct benefits from an integrated child health information system, either because there is no system presently in their state or because their child was born before the system was operational. They nonetheless understand the concept and believe that such a system would be beneficial to children with special health care needs.

Parent A has found the Internet to be "a wonderful resource." She believes that "the Internet can be a great connector [to other families], no matter how rare the disease." She frequently uses e-mail to ensure her child's primary care provider and dietitian "are both on the same page." Parent C also finds the Internet to be an invaluable source of information about her child's disorder. Z believes that the Internet can help with "educating yourself about your disease" and connecting individuals and families to a support groups, "so you know you are not alone."

Parents believe integrated health information systems could help to coordinate their children's health care

Each of the interviewees stressed the critical role the primary care provider plays in making referrals to specialists and coordinating care among them, and believe that most primary care providers do a heroic job. Nonetheless, the parents assume the role of coordinator of care to ensure that no information falls through the cracks. The role requires considerable time, effort, and persistence—a combination that not all parents have.

Parent A said she often coordinates with 5 to 6 different specialists. She has 2 boxes filled with her child's medical records at home, and the primary care provider has a third "huge" file. She described herself as a "very persistent parent, a strong advocate for my child. When you're like that, you can make it work. Not every parent is able to do that. Some parents don't have the time to do what I do." She believes an automated system would help to ensure that information is communicated among her child's providers. However, she noted, that even if such a system were in place, she would continue to ensure that information was communicated among providers.

Parent B believes that the pediatrician needs to be in the center of care, but currently, she says, "It's up to me to make sure specialists are funneling information back to the pediatrician." As her child's coordinator of care, she has a red ring binder that she carries with her from doctor to doctor. Parent B said the burden of coordinating information is tremendous for parents of children with special health care needs. "Some families have to go to multiple providers daily." She also believes that an integrated health information system would help to ensure coordination of care among her child's providers.

To keep herself organized, Parent C maintains a file cabinet at home for her child's medical records. She believes that if the information were available electronically she would be even better organized, and it would improve the quality of care for her child. Parent C also said that because communication lines among providers have been broken sometimes, she has developed "strategies parallel to the system. If I go to a specialist with my child, I take the initiative and go get the information and bring it with me or make sure it's already there."

Z received her care at a children's hospital as a child. When she turned 18, she found she no longer had a medical home to coordinate her health information and her care. Because the hospital for adults did not have her records and was unable to obtain them easily, she believes she was sent for unnecessary tests, was prescribed medication inappropriately, and incurred unnecessary medical bills. Because her medical record was not available, she believes she did not receive good medical care nor was she treated in a caring manner. She said, "With an information system [that has a patient's records], doctors will know exactly what you need, your condition, your medications, and they can be more friendly to you. If they knew what was going on in your body, they would be more sympathetic."

Parents believe information technology can help improve accuracy and timeliness of information

Human error is a concern of parents, and they believe technology can help to ensure information is accurate and timely.

Although Parent A trusts and relies on her primary care provider, she is very concerned about errors in test information. "I check everything. An information system would simplify the process. It would make it easier for parents to double-check information, compare old results to new ones, to track follow-up care." She believes her daughter was fortunate to be born in a European country where the health laboratory operated 24 hours a day, because the predominantly rural state where she now lives might not have diagnosed her daughter's genetic disorder and communicated the

results of the test to the provider soon enough to prevent a negative outcome.

Parent B says one of her jobs is to ensure timely delivery of her child's health information from one provider to another. When a medical record needed to be transferred from an adult medical facility to a pediatric specialist, she had to ensure its arrival in time for the appointment. She said, "I would welcome an electronic medical record for children. It would reduce my anxiety level to know that all the information is there when we walk into a doctor's office."

Parent C believes that human errors are common in medical information, including data that are entered by hand. "People often mistakenly believe that what comes out of a computer is correct," she said. Training of personnel who enter information needs to be emphasized. She believes that many health information errors, as well as the failure to communicate information in a timely fashion, lies with medical office staff rather than the provider.

Parents of children with special health care needs believe health information should be available to those who need it, but safeguards must be in place

Parents want assurance that their children's health information is accessible only when it is necessary. They expressed concern about discrimination against their children and families by insurers and employers. Parents firmly believe that access should be based on how the information will be used, that is, on a "need-to-know" basis. Parents believe the primary care provider is the most important person to have access, followed by subspecialty providers. Other entities that should have access include hospitals, emergency departments, schools, and day care facilities. The interviewees who were aware of the public health role in assurance of health services wanted public health to have access to their children's health information.

Parents A and B believe that security of information has to be the number one priority of these systems. Parent A was especially concerned about the potential for insurance companies to misuse the information. She believes that access should be role related. Although she has concerns that the information could be misused, Parent B said, "I am optimistic that systems can keep information private. The technology is there. The big challenge is to make sure that all with interests feel comfortable with the solution."

Parent C was more conservative about who should have access to her child's information. She said that a child's primary care provider and parent need access to all information, but insurers, [public health] programs, or schools only need to know what is relevant to them. "Access," she said, "should be given based on how it will benefit the child. What works for one family or doctor doesn't work for another." She says parents and service providers need to reach agreement on what kinds of information should be available.

Z, who has a genetic disease, believes that if her school had access to her health information, she would have received more appropriate care. Because she has no visible disability, teachers did not allow her simple, but important, privileges like drinking water in class. She said, "On the outside I look fine, but people don't know what's going on inside."

The interviewees also believe that parents' views must be represented when policies about access to information are crafted. They believe that parents' access to information is often given lower priority than that of providers, insurers, or schools. "Parental access to systems needs more consideration," said Parent C.

Parents believe health information systems can improve health care for their children, but it is not the highest priority health care issue for them

Although these parents believe that information systems can ensure that their children receive more coordinated, accurate, and timely health care, health information systems in general and integrated child health information systems specifically are not their highest health care priority. For families of children with special health care needs, access to subspecialty providers and other subspecialty services, and assurance of health care coverage are clearly the highest health care priorities. For Parent A, access and coverage are definitely higher priorities than information technology. Medication for her child's condition costs upwards of $80,000 annually, and formula costs $400–$500 monthly. However, if her child no longer qualifies for the state children's health insurance program, she would consider moving to a country that offers universal health coverage. She said that the advantages of a child health information system are worth "nothing if you don't have access to health care."

Parent B said that on a scale of 1 to 5 (with 5 being the highest), health information "should be a 3. But is it? No. In the scope of what I deal with daily, it's not something I wake up every morning and think about." But she said, "Families would welcome it being in place. It would mean that my doctor can spend more time with my child and me rather than worrying about records being there."

Parent C said that integrated health information systems have an indirect impact on issues of access to health care and the cost of health care. She says families of children with special health care needs "spend

so much time being bounced around," it's a waste of resources.

Parents believe that their involvement in issues related to children with special health care needs, including information technology, is critical

Tending to the health care needs of children is time-consuming, especially when they have special health care needs. Yet these parents believe that their views must somehow be represented in decisions that have the potential to affect the care of their children.

Parent A said she believes that parents are fortunate to have government programs and private organizations for children with special health care needs and their families to advocate for them, especially when parents' time and financial resources are stretched.

Parent B agreed that it is difficult for families to be involved in the development of health information systems given the burdens many of them must carry. Physicians, she said, have not made information systems a priority. She believes organizations such as Leapfrog, a consortium of businesses that understand the cost consequences of failure to provide accurate and timely health information, will ultimately be the best advocates for these systems.

Parent C also agreed that parents have limited time for direct involvement in advocacy efforts for information systems, but she said parents can make their influence felt by making use of a child health information system one of the criteria for selecting a provider.

Interview With Parent of Children Without Special Health Care Needs

The similar themes that emerged from interviews with parents of children with special health care needs and the young adult with special health care needs raised the question of whether parents of children without special health care needs share these perspectives about integrated child health information systems? The set of 10 questions were used to interview Parent D, mother of 4 children who do not have special health care needs. Parent D was not familiar with the concept of integrated health information systems at the outset of the interview, but was provided with the definition.

Parent D also uses the Internet frequently to get information about healthy development of her 4 children. Although she has 4 children, she has not encountered a problem with the transfer of health information from one provider to another, but understands that it could be a problem if her children had health concerns. She has experienced the burden of ensuring her child's health information is transferred from her pediatrician to schools and camps. Because her 4 children all participate in numerous sports and camps, as well as attend school, she is responsible for collecting the same information many times each year on paper forms, most of which are different from one another. She would like to see integrated information systems provide day care facilities and schools with access to her children's health information, as a matter of convenience.

She believes that information technology can improve routine care for children, such as ordering of tests and medications. Her youngest child was prescribed an antibiotic by the physician on-call and suffered from diarrhea for several days. She recognized that her child's reaction was a result of the medication and confirmed with her child's primary care provider that the dosage was several times what it should have been. Because it was a paper prescription retained at the pharmacy, she will never know if the prescription was written incorrectly by the physician on-call in her practice or interpreted incorrectly at the pharmacy.

Parent D did not have concerns about misuse of her children's health information. She did not believe that, as a parent, she needed direct access to an information system with her children's medical information. She was content to have access through their primary care provider, but wanted day care and schools to have easier access to routine information such as immunization records. She said that although she has coverage and access to health care for all her children, she agrees that, for all families, these issues are of greater priority than child health information systems.

Discussion

The number of interviews conducted for this article is small and cannot be construed as representative of the perspectives of parents with special health care needs or parents of children without special health care needs. Nonetheless, the consistency of responses suggests that the themes identified may be generalized.

The parents of children with special health care needs held strong opinions about their children's health, health care, and integrated child health information systems. These systems are unlikely to be successful without the active involvement of these key stakeholders with the agencies and organizations that are developing the requirements for information systems

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and the policies that guide them. As Ross et al[6] noted in this supplement, "Today, we understand that optimum child health results from a partnership among parents/guardians, their physicians, nurses, and other healthcare providers representing a medical home, and a coordinated public health and health care system, including financing. Future information infrastructure must support and strengthen this partnership."(pSXX)

The Genetic Services Branch, Maternal and Child Health Bureau, Health Resources and Services Administration has recognized the importance of family participation in planning and development of infrastructure to support early identification of children with special health care needs. State genetic planning grantees have made it a priority to involve parents in state genetics advisory boards.[7] In addition, despite the inherent additional burden that attendance at meetings places on family life, parents of children with special health care needs participated in a small workgroup meeting in May 2003 to define the principles and core functions of integrated child health information systems,[8] and in a larger meeting in December 2004 to establish a shared vision of child health information systems that meet medical and public health needs.[5]

Parents are eager to represent the health care interests of themselves and their children, but they have limited time to devote to this issue, especially when they struggle to simply ensure their children have access to appropriate care. Opportunities must be made available and assistance provided when necessary to enable parents in general and especially parents of children with special health care needs to participate in the design, implementation, and evaluation of child health information systems.

Because all children will benefit from integrated child health information systems, systematic research on the perspectives of all parents is needed. However, because families of children with special health care needs are likely to reap the greatest benefit from these systems, special attention must be paid to their perspectives. Such research needs to be ongoing, however, as information technologies and providers' and parents' acceptance and use of these technologies is rapidly evolving.

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