



Rutgers Center for
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**Evaluation of the Transition Process for
Children with Special Health Care
Needs: Final Report**

**Sandra Howell, Ph.D.
Nancy Scotto Rosato, Ph.D.**

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Executive Summary

Introduction

In response to a recommendation by its taskforce on assessing the needs of children with special health care needs, the NJ Department of Health and Senior Services, Division of Family Health Services (DHSS:FHS) identified the medical transition process as an important area to examine as part of their required needs assessment activities. To provide FHS with information about these transitions in New Jersey, Rutgers Center for State Health Policy (CSHP) explored the factors and issues that facilitate successful transitions, as well as those barriers that prohibit the transition or create problems in the process.

Methods

We developed a two-pronged interview approach. First, we interviewed physicians regarding the transition process. Both the pediatric specialists who are transitioning their patients and the adult specialists who are receiving these new patients.

In addition, we interviewed families of children (aged 16 to 21) who are moving towards a potential transition, and families of young adults (aged 21 to 26) who have or should have already transitioned from their pediatric care provider. DHSS:FHS selected a sample of children who had one of five conditions: Cleft Palate; Spina Bifida; Diabetes; Down Syndrome; or Sickle Cell.

Findings

Physician Survey

There were several themes common across all provider types as well as some distinct concerns voiced by pediatric care providers and adult care providers:

- They dealt with these children (adults) as they would any other patients with chronic health care needs,
- Neither pediatric nor adult care providers did anything beyond their normal professional networking to develop relationships with one another,
- Pediatricians did see a difference between autonomous and non-autonomous children, and
- Adult care providers' issues centered on the unpreparedness of young adult patients and parental involvement.

Family Survey

Although different medical conditions were targeted, the issues regarding medical transitioning were the same for all of these families. One of the few differences seen was that individuals with Down Syndrome sought more emotional behavioral services. Another difference among families was the number of specialists frequented and the duration of these visits.

The transition issues for families who had not transitioned their child to an adult doctor included concerns and fears over the transitioning process, and in finding appropriate specialists for their children.

The transition experiences of families who had transitioned their child to an adult doctor demonstrated issues such as difficulty in locating a physician; reliance on insurance companies limiting their choices; a lack of competent doctors who were familiar or willing to take on their child as a patient; and a lack of parental knowledge regarding where to find available doctors.

Recommendations

Clearly, families of children and adults with special health care needs would benefit from having several types of resources and/or information. These include:

- Workshops, pamphlets, or other materials on medical transitioning such as information as to when to start the process, who to ask, what kind of information they should be investigating would be beneficial,
- Statewide lists of recommended providers, specialists as well as generalists, with some kind of description of their patient base (e.g., specific conditions with which they are most familiar) and acceptable insurance,
- Involvement of social service providers (case managers) in relaying information on available services for *adults* with special health care needs, such as available funding for equipment, and
- Communication between pediatricians and adult doctors through the transitioning process, at least initially, so that the process is easier and all parties are informed.

Physicians would also benefit from more assistance from specific providers and information on special needs. For instance;

- Having a case manager to help adolescents move toward adulthood,
- Making parents comfortable about the transition,
- Having consensus between families and physicians about what constitutes a child with special needs whose transition may be delayed or a young adult patient who should be transitioned just like other young adult patients.
- Creating a “transition time”.

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Introduction

In response to a recommendation by its taskforce on assessing the needs of children with special health care needs, the NJ Department of Health and Senior Services, Division of Family Health Services (DHSS:FHS) identified the medical transition process as an important area to examine for their required needs assessment activities. To provide FHS with information about these transitions in New Jersey, Rutgers Center for State Health Policy (CSHP) designed a multi-component project to assist the department with their needs assessment efforts. One component was an in-depth analysis of the 2001 State and Local Area Integrated Telephone Survey (SLAITS) data. SLAITS was conducted on a national sample, but provides each state with its state specific data. Although New Jersey has compared its state outcomes to the national results, a more in-depth analysis of the data has not been conducted. This data would assist DHSS: FHS in better understanding the families' viewpoint on these important issues. A second component would provide an examination of the role of medical providers in the transition process. As children age, they may be moved from pediatric specialists to adult specialists. CSHP explored the factors and issues that facilitate successful transitions and those barriers which prohibit the transition or create problems in the process. This report will provide the details and findings for this second component of our evaluation of the transition process for children with special health.

Background

The current literature regarding children who have special health care needs and their families deals with a wide range of issues from the financial and insurance impact, to the stress of caregiving, to the need for social and support services. Focusing on these issues, the *Journal of Maternal and Child Health* published numerous articles in 2005 which examine the needs of children with special health care needs across various states.

For instance, in examining families in New Hampshire who were interviewed in the National Survey of Children with Special Health Care Needs, Bumbalo and colleagues (2005) found that parents of children with special needs were 14 times more likely to need care coordination than parents whose children do not have special needs. These families are also more likely to have public insurance, inadequate insurance, and higher out-of-pocket costs. Tippy, Meyer, Aronson, and Wall (2005) also found similar results in Maine. In particular, these families were also less likely to have ongoing comprehensive care in a medical home. Likewise, Rosenberg et al. (2005) found that one quarter of families in Illinois reported a need for care coordination, and that this need for coordination was related to condition severity, lack of insurance, and inadequate communication with providers. These studies suggest that parents and their young adult children with special health care needs require more assistance with their transition to the adult care medical providers.

While there is evidence of the additional needs of these families in dealing with the complex issues of having children with special health care needs, we also reviewed the research that focuses on the transition between pediatric and adult care. Included in this literature is research discussing the need for adult care specialists for illnesses that were once primarily considered an issue of childhood care. Sickle Cell Disease is one such condition where few pediatric patients survived into adulthood. However, with recent advances in medical care, more children are now living well into adulthood, these young adult patients now needing to transition to adult care providers. While one study found that patients with Sickle Cell do require medical sub-specialists at times, children with this condition could be viewed as children with a chronic health condition who will be increasingly managed by general medical providers (Harvard, 1999). Although much of their outpatient management can be handled by an internist, the children and their families are still in need of help with their transition to adult care providers. One Harvard report on transitioning children who have Sickle Cell found that these children, as with all children with a chronic illness, face more complex challenges in finding new care providers, and often need more help and guidance throughout the transition period (Harvard, 2000).

While there has been significant discussion about the assistance that families need when their children transition to adult care providers, the type of assistance needed and

who should provide it is the issue. Specifically in question is the role that physicians should assume, as well as the tasks that could be performed by specific types of care management providers. One study of 753 parents of transitioning children with special health care needs, and of 141 health care providers (mostly pediatricians), focused on the perceived role of the care provider during the transition. Interestingly, providers described themselves as having bigger roles in the transition activities than the parents felt they should have. Parents felt that the “provider’s major responsibility was for direct health maintenance or coordinating their child’s health or coordinating their child’s health care with other health care providers.” They also felt less certain that providers should be involved in discussing drugs, alcohol, and sexual issues with their children. In contrast, providers felt that the children should begin the transition process earlier including being more autonomous during the medical visits (Geenen et. al., 2003).

While providers may feel that the young adults should be more autonomous, the families of children with special health care needs are much more involved in the health care of their children. In one study of communication patterns of primary care, Burstein et.al.,(2005) found that providers did not differ in their communication patterns between families with children with special health care needs and those families of healthy children. Parents of children with special health care needs, however, were much more involved in terms of communication, sharing information, and asking questions. In another study of barriers to pediatric health care, Sobo, Seid, and Gelhard (2005) found that successful parents were those who understood the health care system’s culture and had learned how to competently function within its parameters.

Across these studies, several themes are clear. Families with children with special health care needs face a myriad of complex and intertwined challenges (e.g., financial, insurance, impact of caregiving). As their children move towards adulthood, they also face the need to transition these young adults from their pediatric care providers who are familiar and used to working with these families to adult care providers who traditionally work adults with chronic illness.

Methods

We developed a two-pronged interview approach. First, we interviewed physicians regarding the transition process. Both the pediatric specialists who are transitioning their patients and the adult specialists who are receiving these new patients were included in the interview sample. To develop the sample, we stratified randomly selected NJ physicians derived from a CSHP/ Board of Medical Examiners project list. Originally, 40 physicians were selected. Due to lack of participation, we also used snowball techniques to increase the respondent pool. Specifically, we contacted several Maternal and Child Health Consortia directors and asked them to recommend pediatricians (this method generated 9 additional physicians). The interview instrument explored the factors and issues that facilitate successful medical transitions and those barriers which prohibit the transition or create problems in the process. Some of the questions were:

- What types of networks and contacts do these physicians have with one another to assist patients in the transition process?
- Who (pediatric specialists, adult specialists, case managers, etc.) assists the patients and their families in this process?
- Are the adult specialists available and able to handle these transitioning pediatric patients?
- What is needed by these specialists (pediatric and adults) to make the transition easier and more successful?

Second, we interviewed families of children (aged 16 to 21) who are moving towards a potential transition, and families of young adults (aged 21 to 26) who have or should have already transitioned from their pediatric care provider. DHSS:FHS selected a sample of children who had one of five conditions: Cleft Palate; Spina Bifida; Diabetes; Down Syndrome; or Sickle Cell. These families were contacted by DHSS:FHS to inform them that they may be asked by CSHP to participate in this study. Once families were contacted, their names and contact information were given to CSHP. We then drew stratified random samples based on age and condition. Selected families were contacted and asked to participate in the study. CSHP explained that study participation was voluntary and confidential, and obtained consent to participate. Rutgers University IRB

and DHSS IRB approval was obtained to oversee the human subjects aspect of both phases.

The interview instrument explored the factors and issues that facilitate successful medical transitions and those barriers which prohibit the transition or create problems in the process. Some of the questions that were asked include:

1. Did your care provider bring up your child moving to an adult care provider?
2. Have you and the child's care provider discussed your child's changing health needs as they become an adult?
3. Are there any concerns regarding transitioning your child from pediatric care to an adult physician care?
4. What resources would help you during this process (or would have improved the process)?
5. How has your child adapted to the transition?
6. What role did your pediatrician play during this transition process?
7. If you had to go through the medical transition process all over again, what would you do differently?

The entire copy of the family questionnaire is enclosed in the appendix.

Physician Survey

In total we spoke with 9 physicians. Although the number of physicians was small, there were several themes voiced across all provider types as well as some distinct concerns mentioned by pediatric care providers and adult care providers. All physicians said that they dealt with these children (adults) as they would any other patients with chronic health care needs. Neither pediatric nor adult care providers did anything beyond their normal professional networking to develop relationships with each other. Pediatricians did see a difference between autonomous and non-autonomous children. Some said that those who were significantly cognitively impaired did not have to transition. For one physician, non-autonomous children remain in the pediatric practice and continue in the traditional pediatrician-parent care model. Those they considered autonomous (able to make their own decisions) were thought to transition as any other young adult, although they may do so a bit later. Another pediatrician said:

“What I usually do is keep them as long as I can...even though there is a restriction on how long a child can be with a pediatrician—24 to 25 years---I still try to take care of them until they are older. It’s very hard to transition them smoothly, especially those that are more handicapped.”

One issue was the definition of “special needs.” One pediatrician said that if by special needs one is referring to children with a chronic disease, then they should transfer, because they are no different than anyone else. She defines special needs as “needing highly technical care and significantly ill—approaching hospice care.” These children she would not transfer.

With respect to whether adult specialists were available and able to handle these transitioning pediatric patients, the feeling was that this was not an issue, although one pediatrician felt that a caseworker could help in the transitioning. Specifically, they can help in making the transitioning process smoother by educating the adult physician on the needs of that particular client & the sensitivities needed. On the other hand, the adult care providers’ issues were not about handling the incoming special needs young adult. Rather, two salient issues for them were the unpreparedness of young adult patients and parental involvement. Adult care providers shared that they were often the first to discuss adult topics such as sex and alcohol use with these patients. According to one physician, both of these issues were already salient for several of her patients, and could have had significant adverse effects due to their conditions. However, pediatricians said this was part of their routine care. Another issue was the presence of parents. Adult care providers often felt their patients would be more comfortable discussing these adult issues if their parents were not in the room. They related that they often asked the patients if they wanted their parent in the room, but this seemed to cause some tension with parents who were used to being included. These issues were also noted in the literature (Burstein, et.al., 2005; Greenen et.al., 2003).

In terms of what is needed by these specialists (pediatric and adults) to make the transition easier and more successful? The suggestions include:

- Having an active transitioning team, case manager included, able to deal with the difficulty of adolescents & moving toward adulthood.
- Working with the parents who are comfortable coming to a pediatric program, but who need to transition.
- Education for adult physicians/clinics that deal with children with special health care needs, establishing a “mindset” of the patient, family, and physician, even if the patient is now an adult.
- Have a “transition time”.
- Have those people (family, doctors, and social workers) involved in the child’s life provide a supportive, understanding environment.

Family Survey

To further explore the issue of medical transitioning, we spoke to 16 families who had a child with a special health care need. Eight of these families had a child with Down Syndrome, 4 had a child with Spina Bifida, 2 had a child with Diabetes, and 2 had a child with Cleft Lip and Palate. Unfortunately families with children who had sickle cell anemia were not available to be interviewed or refused to participate.

The majority of these parents (n=9) had not transitioned their child from a pediatrician to an adult doctor; however, most were aware that transitioning needed to occur in the next few years or so. The age range of the youths who had not transitioned was 16 to 21, with an average age of 18. The age range of youths who had been transitioned was 18 to 26, with an average age of 21.

Although different medical conditions were targeted, the issues regarding medical transitioning were the same for all of these families. One of the few differences seen was that individuals with Down Syndrome sought more emotional behavioral services. Parents of these children reported obtaining counseling and therapy for their child either at school or other locations more often than parents of children with other conditions. However, obtaining emotional and behavioral services was generally not reported very often among this group of families.

Another difference among families was the number of specialists frequented and the duration of these visits. For example, individuals with cleft lip and palate saw fewer specialists but saw them more frequently and more intensely over a shorter period of time; while others saw more specialists over a longer duration. Nevertheless, when questions regarding medical transitioning were asked, differences between families with children with different medical conditions disappeared.

Locating a Provider: Concerns, Fears, and Expectations

Families Who Have Not Yet Transitioned

A number of families who had not transitioned their child to an adult doctor (n = 7) expressed concerns and fears over the transitioning process. One mother was worried that she wasn't able to find the "right" adult doctor that would understand her child's condition. Others were concerned that an adult doctor would not be as sensitive, understanding, or attentive. One mother expressed this succinctly:

"You can say that pediatricians are a different breed of doctors. They are much more likely to spend time with you, ask questions, take a personal interest. I'm afraid we won't find that in an adult doctor."

Several mothers (n = 8) were also concerned about finding appropriate specialists for their children. One mother stated that "specialists usually don't look at the total person, just their area of specialty" and that becomes a problem because the medical condition usually affects many facets of the child's life. Although many of these children are currently seen by specialists on a routine basis, not all of them accept adult patients; therefore, many families are faced with locating new specialists as the child transitions to adulthood. Some parents (n=5) believe that finding a specialist is even more important than finding a general doctor, partly because they see these specialists more frequently and partly because they are more difficult to locate. In fact, there is a shortage of specialty providers in New Jersey (Cantor, Brownlee, & Huang, 2006). One mother discussed her desire to find an adult physician, including a specialist, that is not only competent but interactive.

“Adult providers are so unnerved when caring for children with special health care needs and even our endocrinologist said that there aren’t many good ones out there. I don’t want to go to someone who just “treats,” but to someone with a personality, knowledge, and experience.”

Nevertheless, a few mothers (n = 2) did believe that finding a new doctor was not going to be a problem, citing that their pediatrician or child specialists would refer them to someone. For example, when asked if she was worried about finding a new doctor, one parent responded:

“Not really. I’ll just get a referral from the pediatrician. It’s better if it comes from him because of familiarity. He is familiar with my child’s condition and so he can recommend someone who may be familiar.”

Others (n = 2) just assumed that their child will be going to their doctor or the “family doctor,” the same as his/her siblings. These parents were not overly concerned about finding an adult physician because they did not depend on the primary care physician as much as they did on the specialists. Additionally, these children were not as close to transitioning and in fact, had not discussed the transitioning process at all with their pediatrician.

Transitioned Families

The experiences in locating a physician varied among families who have transitioned their sons or daughters to an adult provider. Some (n = 3) said it was a process of trial and error. Others (n = 5) relied on their insurance companies. However, this was not always seen as the best method because the choices were very limited. One mother described this process and how she made her decision:

“[It was] not a problem at all [in selecting a physician from the insurance company directory] but there weren’t a lot to pick from. I had a choice of two that were close to home and so I went to both and picked the one I liked the best.”

Although these families were active in selecting a provider, the majority of them felt constrained due to the limited number of available providers. Much of this limitation had to do with insurance companies but other reasons included the location of the families' residence, a lack of competent doctors who were familiar or willing to take on their child as a patient, and a lack of knowledge on the part of parents regarding where to find available doctors.

For a few of the families who transitioned their child (n = 4), the pediatrician was not only helpful in the transitioning process but also in assisting them in asking the "right" questions. One mother stated:

"The pediatrician was really helpful. Not in finding doctors but in telling me what I should ask. She told me to ask about the hours of operation, whether they had extended hours, whether they have coverage if your doctor is not available."

This parent believed that her pediatrician did the best she could by providing her with these questions, questions that she would not have thought of on her own. In fact, this advice helped her tremendously in finding an appropriate provider for her daughter who had diabetes.

Regardless of the method used to locate a provider, not all of the families (n = 4) who transitioned their child to an adult provider were satisfied with the provider to whom they transitioned. Dissatisfaction with their new providers' knowledge (or lack thereof) of their child's condition was especially problematic, causing the burden of decision-making and information seeking of certain procedures on the parent. For instance, one mother said:

"I wanted someone who was familiar with my child's condition but he [the adult physician] doesn't know anything. I'm left with a lot of the decision and I don't know what I'm doing all of the time. I don't have a medical degree."

This parent not only expressed how overwhelmed she was with the decisions she had to make but also the fact that she had felt constrained in selecting a provider. She

felt that she had “settled” for someone who was passable but not really familiar with her child’s condition.

Changing Health Care Needs

Parents (n= 8) who had not transitioned their child had also not talked about the changing health care needs of their child. The reason most cited was that the pediatrician did not raise the issue and they did not feel comfortable (or did not think about) asking the questions about their child’s health needs as adults. Another reason reported was that at the present time, school to vocational transitioning was more important to the parent than medical transitioning. Any discussion of changing health care needs would occur when the child moved to the adult provider.

Barriers Encountered or Expected

Health Insurance

The majority of children (n= 12) were on their parents’ private insurance regardless of whether they were transitioned or not. A few of these children had a combination of private insurance and Medicaid (n = 4), and four children were only on Medicaid. Based on the responses of parents, insurance played a big role in the type of care an individual received. Parents with children who had Medicaid reported that their children saw different pediatricians within a group practice every time they visited. They felt that the pediatrician was not particularly connected to their child and reported that these pediatricians relied on files and charts to get the information and make decisions about their child’s health rather than actually “knowing” their child.

Parents with children covered by private insurance reported problems related to lack of coverage. A few of these parents (n = 4) restricted the procedures that were covered by their insurance company. One parent said that when her child was born with cleft lip and palate, the hospital told her that it was a “birth defect” and not covered by her insurance company, resulting in her having to pay for several procedures out-of-pocket. Other parents reported that even when they obtained prior approval from their insurance company, the insurance company refused to pay or did not pay as much as

promised after the procedure, placing the burden of paying for the services on the families.

Several of the parents with children who had not yet medically transitioned (n= 5) had not discussed or even thought about their child's changing health insurance status as adults. The main reason for this was that coverage from their insurance company was still possible for at least a few years. One parent stated that with the recent legislation in New Jersey extending the age for dependents to be on their parents' or guardians' insurance until the age of 30, she was not worried about the changing insurance status. Finally, a number of parents reported already having children on Medicaid so they were not worried about their insurance changing or going away as adults.

Office Environment and Staffing

Several parents of both transitioned and non-transitioned children reported encountering environmental barriers at doctors' offices. A few had problems with the basic layout of the waiting area, with the size of the room, or the placement of the chairs being a big problem. One parent shared her daughter's experience at a radiologist's office. Her daughter had Spina Bifida.

“The radiologist in our plan was horrible. My daughter couldn't get through their waiting area. The chairs were in the way and they [office staff] got mad at us when we moved them out of the way.”

Other parents (n = 3) were dissatisfied with the available equipment in a doctors' examining room, wishing that their doctor had more accommodating equipment such as a hydraulic table.

Numerous parents mentioned office staff being an important component in not only selecting a doctor but also in remaining there. One parent mentioned that she changed doctors because the nursing staff was not able to communicate with her child successfully during a blood extraction procedure. Another parent who was in the process of selecting an adult provider mentioned how important it was to her and her child that the office ambiance was positive.

“How nice people were in the office and the whole flow of the office was very important to me. If the receptionist was nice or if the office manager was friendly and provided a positive vibe then I liked the office.”

Parents, regardless of whether their child was transitioned or not, felt that the physical environment as well as staff attitudes and behaviors contributed a great deal to a successful doctor to patient connection. Problems in any of these facets caused dissatisfaction and barriers to successful health care.

Culture and Language

Few parents mentioned that cultural incongruence between themselves and a provider was a problem. However, several (n = 4) did mention the provider’s belief and attitude toward individuals with special health care needs was an important factor in the decision to retain a provider. These parents felt that a provider should treat their child with independence and dignity by talking to the child directly about his or her health and not to their parent or guardian. Selecting a provider that was able to do this was very important to these parents, although they felt that it was very difficult to find this type of provider.

Even though family culture was not reported to be a barrier for these families, language was a problem for one parent in this group. Not being able to speak English and having a provider that did not speak her language became problematic in not only understanding her child’s condition but also in the decision-making of her child’s changing health. As this parent reported:

“I don’t speak English. Maybe if I spoke the language I could ask many questions and confront the doctors. However, I don’t which makes it much more difficult. I feel like not speaking English is a like a barrier to me. It makes me feel empty, giving me a feeling of not knowing.” [Translated from Spanish into English]

This parent clearly saw her inability to speak English as a barrier to obtaining appropriate care for her child. She felt alienated and powerless not only in inquiring about her child's health condition, but also in questioning whether the doctor's decisions regarding the course of treatment were appropriate for her child.

Resources: Used, Needed, or Wanted

Families who had medically transitioned their child did not utilize a great deal of resources. Some used pediatricians (n = 4). Others used their insurance company directories (n = 2) and one family said that they used no one at all.

When families who had not transitioned their child were asked about the kinds of resources they had to assist them in making the decisions regarding transitioning, the majority of them (n = 5) cited their pediatrician. A few families (n = 3) cited state or national associations such as the Spina Bifida Association. Only two families stated that they would get information from other parents in the same situation.

When asked, ideally, what kind of resources they would like to have available to them during the process of medical transitioning, most (n = 7) wanted a list of doctors that specialized in their child's condition. Not only a list of specialists that they could select from but also lists of general doctors that were familiar with their child's condition and could make informed decisions. One parent even went so far as suggesting that these doctors should have a rating or a recommendation level given by other parents.

“Have a mechanism with specialists and other doctors in the area who work with children with special health care needs. Have parents' reviews as part of this list, like they do with hotels, such as 50% of parents found this specialist to be satisfactory”

Several parents (n = 5) also reported wanting additional information regarding the transitioning process aside from a list of providers. A few parents wanted informational workshops on the medical transition process itself, possibly given at their child's school. Others wanted specific information through a workshop, pamphlet, or a caseworker on such topics as Medicaid laws and resources and/or services available to *adults* with

special health care needs such as a place to call to request for needed equipment. These parents all knew that these were “ideal” requests and most felt certain that these services were not available.

Conclusion

Since the number of responding physicians was small, we do caution the generalizability of these themes, but we did find a lack of any “special” networking either from the pediatric or the adult care providers. Among these physicians, there was some consensus, that children with chronic issues such as diabetes should be handled like all patients with a chronic illness. In fact, this feeling led to the question, “What should be considered ‘*special needs*’?” For children with cognitive issues, pediatric providers were more likely to ‘hold on’ to these patients longer than other adult-children. On the other side of the transition, the adult care providers felt these patients should have been treated more like young adults which includes discussions of sexual health and how the parents participate in the doctor-patient relationship.

Medical transitioning was a difficult process for some families. Most went through it uninformed, knowing that it was a necessary process but not knowing exactly how to proceed. For some, pediatricians were helpful in terms of what to ask or look for in a good adult care provider. Other families felt that they had “settled” for what was available and not for what was most appropriate for their child.

Families who would eventually experience medical transitioning clearly expected to have a highly involved pediatrician who would inform them of when the time to transition should begin and to provide referrals. However, many were aware that the medical transition process involved many other components such as changing health needs and insurance status and wanted guidance through other sources such as their child’s school or their case managers. Most of these families were not naïve with respect to this process, regardless of whether they went through it or not. Perhaps this is because there are many other transitions in their child’s life, including educational transitions. These families encountered (and for some, are still encountering) many barriers but as one parent stated, “don’t be afraid to ask questions and challenge. Doctors don’t always know everything.” This is one way of overcoming health care barriers.

Recommendations

Clearly, families of children and adults with special health care needs would benefit from having several types of resources and/or information. For example,

- Workshops, pamphlets, or other materials on medical transitioning such as when to start the process, who to ask, what kind of information they should be investigating, would be beneficial.
- Statewide lists of recommended providers, specialists as well as generalists, with some kind of description of their patient base (e.g., specific conditions that they are most familiar with) and acceptable insurance.

These families would also benefit from more assistance from specific providers. For example,

- Involvement of social service providers (case managers, DDD) in relaying information on available services for *adults* with special health care needs, such as available funding for equipment.
- Communication between pediatricians and adult doctors through the transitioning process, at least initially, so that the process is easier and all parties are informed.

Physicians would also benefit from more assistance from specific providers and information on special needs. For instance,

- Having a case manager to help adolescents move toward adulthood.
- Making parents comfortable about the transition.
- Having consensus between families and physicians about what constitutes a child with special needs whose transition maybe delayed or a young adult patient who should be transitioned just like other young adult patients.
- Creating a “transition time.”

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Appendix

Family Interview Guide

- 1) Does your child have a usual source of care? Probe for:
 - a. What kind of place is it? (e.g., doctor's office, hospital emergency room, hospital outpatient department, clinic or health center, school)
 - b. Does he/she see a: general doctor, pediatrician, nurse practitioner, physician assistant, other specialist?
- 2) Is this healthcare provider in a group practice or solo practice?
 - a. Probe for: is he/she with other pediatricians or with other doctors with different specialties?
 - b. Do these other doctors specialize in your child's condition as well or are they general physicians?
- 3) How long has he/she seen this particular healthcare provider? Probe for:
 - a. Does he/she specialize in your child's condition or is he a general physician/pediatrician/nurse practitioner?
- 4) Will he/she continue with this provider? Probing:
 - a. Are you and your child satisfied with this provider?
 - b. Is this provider still willing to retain your child as a client?
- 5) Does your child obtain specialty care?
 - a. Probe for: is this specialty care usually referred to by the [usual source of care] or do you locate the specialty provider yourself or through your insurance plan?
 - b. How often within a year does he or she go to specialist?
 - c. How much of a problem is it in locating the right specialist?
 - i. What are some problems you've encountered, if any? Finding one, distance/transportation, making an appointment, obtaining approval from your insurance plan etc.
- 6) Does your child obtain any emotional or behavioral services?
 - a. Who does he/she go to?
 - b. Does he/she speak to a (specialist) pediatric psychologists/psychiatrist or does he/she speak to his/her pediatrician?

IF SPEAKING TO A FAMILY WHOSE CHILD IS BEING TRANSITIONED

- 7) Did your care provider bring up your child moving to an adult care provider? Probe for:
 - a. Why did your health care provider bring this up?(Probe for:
 - i. He/she is moving towards adulthood & it's necessary by law?
 - ii. He/she is moving towards adulthood & the provider is suggesting it's time.
 - iii. He/she is moving towards adulthood and you think it's the right time.

- iv. He/she is moving towards adulthood & your child thinks it's the right time.
 - v. He/she is moving towards adulthood & your child's caseworker/social worker thinks it's the right time.
 - b. How old was your child when they talked about this?
 - c. Were you interested in this? Unhappy about this?
 - d. Did they say they would help with transition?
 - i. If yes, in what way?
 - ii. Did they refer you to someone?
- 8) Have you and the child's care provider discussed your child's changing health needs as they become an adult?
- 9) Have you and your child planned for any changes in insurance status?
- a. Will your child be Medicaid eligible or would he/she still be on your insurance plan or would he/she need to look at other sources of insurance?
 - b. Is this affecting your selection of which adult provider to go to? Or in getting specialty care?
- 10) Are there any concerns regarding transitioning your child from pediatric care to an adult physician care? If yes, what are they? Probe for: Are you concerned with:
- a. The lack of availability of providers who specialize in your child's condition?
 - b. The lack of knowledge of this new provider regarding your child's condition and family history?
 - c. Not knowing if your child will adapt well with this new person?
 - d. Not knowing if this new provider will be as supportive or understanding as the pediatrician?
 - e. Your child being among adult patients?
 - f. Not being sure if this new provider's office being physically accommodating to your child's needs (for example, having hydraulic table available so that that your child who is in a wheelchair can easily transfer himself/herself to the examining table or have staff available for assistance if needed etc.)
 - g. Not being sure if this new provider is culturally competent—linguistically, ethnically matched or understanding of your culture and mores.
- 11) Are there enough resources available to you to assist you and your child with this transitioning? Probe for:
- a. Based on your location of residency and availability of providers do you think you have enough choices in the adult providers to choose from?
 - b. Where are you looking to locate potential providers? (internet, discussion with other parents, pediatrician)
 - i. Are these places/resources readily available to you?

12) Is anyone assisting you (or has anyone assisted) with this process and if so, how?

Probe for:

- a. Current usual source of care (pediatrician).
- b. A case worker/ coordinator
- c. Other family members.
- d. Other parents in the same situation as you.

13) What resources would help you during this process (or would have improved the process)? (Probing will include elaboration of how these resources would help or improve the process, suggestions they have etc.)

IF SPEAKING TO A FAMILY WITH A CHILD WHO HAS ALREADY EXPERIENCED A TRANSITION

7) During the transition process, what resources were most helpful to you? Probe for:

- a. The pediatrician (usual source of care)
- b. The internet
- c. Other families going through the same things.
- d. Case worker/social worker
- e. Others...

8) Did you feel you had enough resources available? Probe for:

- a. Based on your location of residency and availability of providers do you think you have enough choices in the adult providers to choose from?
- b. Were you able to find a provider with a office that is physically accommodating to your child's needs (for example, having hydraulic table available so that that your child who is in a wheelchair can easily transfer himself/herself to the examining table or have staff available for assistance if needed etc.). Was this important to you?
- c. Were you able to find a provider that was culturally competent— linguistically, ethnically matched or understanding of your culture and mores? Was this important to you?

9) How has your child adapted to the transition? Probe for:

- a. Is he/she happy with this new provider?
- b. Has the transition been smooth?
- c. Do you think the decision was the right one?
- d. Do you have any major concerns regarding this adult provider?

10) What role did your pediatrician play during this transition process? Was it adequate? Probe for:

- a. Could he/she have had a bigger role? Smaller role?
- b. Would you have preferred some other resources aside from the pediatricians?

- c. Did you feel he/she gave you enough choices of adult physicians? Probe for:
 - i. How much information did he/she give you about these adult physicians?
 - ii. How much direction did he/she give you in selecting an appropriate physician?

- d. If you had to go through the medical transition process all over again, what would you do differently? Probe for:
 - a. What would you have liked to see differently?
 - b. What would have made it more effortless? Less difficult?