

COMMENTARY: PART II

Transitioning from Pediatric to Internist Physician for Adults

Deborah and Joseph Switalski

Mr. and Mrs. Switalski have two children with special health care needs and currently live in Phoenix, AZ.

As our children grow, we as parents must also grow with them and help them transition to the next level. The transitioning starts in school and begins the series of steps our children need to take toward independence. The biggest transition of all is the transition from high school to post-high school and then more dramatically from pediatrician to internist. In some ways, the transition from the pediatrician can be one of the hardest because it involves the person who has consistently watched over our children for the longest time. If your family has a child with special needs, this transition can be even more unnerving, as it can mean moving from a secure and safe relationship to an unknown source and level of care. In our case, we have two sons born with cerebral palsy, which we later learned was a result of a fairly rare condition known as Pelizaeus-Merzbacher disease that prevents the myelin sheath from fully forming and covering the nerve tissue. Both sons are alert, social, and small in stature, with significant hypotonic and spastic muscles. Our older son has asthma, allergies, and a generally compromised respiratory system that leaves him vulnerable to frequent infections and periodic episodes of pneumonia. Our younger son has had four different intra-theal pumps installed over a 17-year period in order to deliver baclofen to his lower extremities to prevent constant spasms, clonus, and pressure from his knees pressing together. Through all of the hospitalizations our sons have endured, we could count on the children's hospitals in Detroit, Kansas City, and Phoenix to provide not only great and responsive medical care but also the extra measure of compassion that comes from

every aide, nurse, medical student, intern, resident, attending, hospitalist, and physician specialist that cared for them. This extra level of care and love appears to be a hallmark of the children's hospitals we have encountered regardless of physical location.

As we look to make this transition, we need to understand the differences between staying with a family medicine doctor or moving to an internist or a specialist that our child will need. Choosing a primary care physician can be an overwhelming quest, as it requires understanding the differences between them and then deciding which one will offer the best support system of care. For some, the choices are decided for them by their work or further schooling—for others, by state support.

Many pediatric offices offer a multidisciplinary team (MDT) to provide the care for children with special needs. The benefits of an MDT are tremendous. In an MDT, one person becomes the main coordinator of care based on needed medicine and therapies as well as the child's medical status. Regular meetings ensure key issues are brought up and discussed to develop *coordinated*—not needlessly repetitive—care. If the team holds clinics, specialists that families don't always encounter, like nutritionists, social workers, and occupational therapists, are available to stop in and let families know about available resources. In addition, we have found that all providers are notified when our child requires hospitalization. As a parent, it was reassuring to have the physicians and specialists stop by our child's room to see him even when admitted for a procedure not in their area of expertise.

This personal touch was somehow prevalent in the pediatric arena regardless of episode. With all subsequent specialist appointments, information flow was coordinated, allowing everyone to understand the details of the hospitalization. The fact that the system supports and encourages physicians to get to know our children holistically and personally seems to be a hallmark of a children's hospital. This support system is very comforting, but it creates anxiety when similar support systems are not available in the adult setting where several doctors work as a team to provide care. The idea of screening new doctors in separate offices—knowing that we are responsible for obtaining all necessary information—is an overwhelming burden. Without the electronic health record (EHR) in place, obtaining, transferring, or ferrying our children's appropriate health records to separate offices becomes a full-time job. I don't have to mention how frustrating it is to have to complete the same sometimes-lengthy medical forms for each new facility or physician visited.

The community health support system options are simpler during the pediatric ages and are based mostly on services connected to the hospital. Once special needs children reach an adult age, their options regarding social agencies, insurance plans, and hospitals are huge and varied and so overwhelming that one doesn't even know where to begin to ask questions. The insurance plan becomes the main guide—not the services provided by the hospital. For us, simple things like finding an urgent care clinic, eye doctor, dentist, or a lab

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filled us with uncertainty. We now know we need to do a lot of calling around first to see where our sons can be seen. For example, while we were in the transition process, our older son had an ear infection on a weekend. Not knowing yet where to go, I took him to his usual weekend urgent care clinic. We had been warned our sons might be turned away for care there after a certain age. That is exactly what happened. When I asked where we should go, some local urgent care clinics were recommended, but no one was sure they were appropriate for our son or would take our insurance plan. Not knowing where to turn, I headed out the door to go home and start calling. Later, I was called back in, and the clinic provider examined my son's ears, wrote a prescription, and then mentioned some possible places to go for special care. I knew at that point that I had to be better prepared in the future. Calls are now made ahead of time to a physician or agency based on personal contacts or other family recommendations. The question of insurance often comes up in deciding where to go next. Will the medical center or physicians group honor the same insurance plan as the pediatric facility? If not, what are the options? Do they see adults only or all ages? These seem like such small things, but to sit in a

waiting room and be told that the clinic does not have equipment small enough to examine your son or that the group is not contracted with your current insurer can be scary and overwhelming. This scenario often occurs at referred adult facilities, and the parent is then charged with the task of pre-contacting the facility to make certain it can accommodate the special need or smaller body size.

We have been fortunate that we have found our way through all of this uncertainty and received a lot of positive support from our new physicians. The many tears shed and frustrations experienced in the search are now forgotten. I can't help but wonder if some of it would have been less stressful if we had been better prepared by the pediatric facility and armed with a checklist of issues to consider before beginning the transition process and facing all of the new decisions that had to be made. A checklist might contain items such as:

- Recommendations for new internists familiar with pediatric care in systems that have the specialists needed for the child's diagnoses;
- Recommendations for hospitals, physician groups, and clinic systems that are contracted with the child's existing insurance provider;
- A complete medical record assembled for parents so that they can present a complete patient picture of the special needs child to the receiving PCP, hospital, and physician group;
- A face-to-face meeting or phone conference between the child's PCP in the children's hospital system and the receiving PCP to review the medical history and treatment plan; and
- A thorough review of records by the receiving physician to facilitate referrals to in-network specialists and urgent care facilities that are equipped to handle the needs of the patient.

The bottom line is that parents with special needs children know that such transitions are difficult and that they must assume the role of advocate. However, it is much easier to approach that task with a partner. Someone from either the sending system (i.e. children's hospital) or the chosen receiving system should take a personal interest in making certain the child is cared for properly in the transition. This is best accomplished when all of the critical issues are addressed in a checklist and an open dialogue occurs with the parents as the checklist tasks are addressed and completed.

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