Abstract

About 18% of all children in the United States have complex medical diseases, require technologic support, and/or have developmental or intellectual disability. These children require routine or maintenance care through the medical-home model. However, due to a lack of physicians, time, and financial constraints it is difficult for many of those children to obtain this care. Pediatricians often lack the training (or comfort level) to care for these children in the office setting. Having an understanding of what outpatient care entails to better serve this population will help the pediatrician provide a medical-home setting for children with special needs and their families. [Pediatr Ann. 2015;44(12):522-525.]

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The American Academy of Pediatrics established the “medical-home” model in 2002. The purpose is to provide continuity of medical care, coordinated care with other health professionals, and care that is family-centered and culturally sensitive. The medical home is designed for all children with special needs to ensure growth and development, vaccinations, screening tests, and care of acute and chronic illness.

For the children who have special needs (roughly 18% of all children in the United States) these “routine” visits are neither simple nor straightforward. Children with special needs have complex medical disease, require technologic support, have developmental delays, with or without physical disability, or intellectual disability. Their care plans are more extensive, the medical and social needs are different, and the physical examination is more difficult to perform. Providing maintenance care is important. Unfortunately there are not enough pediatricians to care for these children in an office setting due to time and cost restraints, or lack of experience and comfort with children who have special needs. This article discusses the office-based care of the child with special needs so that the pediatrician can ultimately provide an adequate medical-home setting.

UNDERSTANDING WHO THEY ARE AND WHAT THEY NEED

Most families with children who have special needs want to raise them at home. Advances in technology, support services, such as home nursing and therapies (physical, occupational, and speech), and changes in laws (Supplemental Security Income, federal education laws, Katie Beckett Act, Americans with Disabilities Act, and Affordable Care Act), make this possible.

At the center of providing the medical-home care is the child. It is important to be knowledgeable of the diseases or illnesses that afflict the child. Many children have unique chromosomal defects, neuromuscular diseases, or metabolic disorders only read about in medical school. Cognitive or intellectual disorders may also be present. Research the condition that the child has and become knowledgeable. This makes it possible to monitor for short-term and long-term complications. If when seeing the child for the first time,
you don’t understand the condition, then ask the parent to explain it to you.

Become familiar with the equipment that these children may require. Children with special needs often have ventricular shunts, tracheotomy tubes, gastrostomy button, jejunostomy tubes, vests and cough-assist equipment for respiratory care, and wheelchairs. At home they may require prone standers, wedges and splints for joint management, special bedding, and pulse oximeters. Ask about the home: does it have ramps, bath chairs, and hydraulic lifts (Figure 1). Furthermore, there are some common terms that the pediatrician should master when working with children who have special needs (Table 1).

Get to know the family (natural, foster, adoptive, guardian, extended) and their support systems. Family support systems allow for permanency of care, which focuses on establishing relationships and involvement in the community, and not just medical care. Is the home a two-parent home, a single-parent home, and are siblings present in the home. Often the child with special needs has care with one pediatrician, and siblings with another. Does the immediate family have support from grandparents, friends, or neighbors?

Know what services are available to the family and child: is the child enrolled in an early intervention program; does the child have an individual service plan, or an individual education plan for school; is the child homeschooled; and is there a school or at-home nurse. Respite planning is also important to ask about. The health insurance status is important to know due to insurance network procedures for subspecialty care, hospitalization, emergency department visits, and prescribing medications. The families of children with special needs have large financial responsibilities, so limiting costs is critical.

Pediatricians should also understand the legal rights of the children and their families regarding education, respite, and community access.3,5

OFFICE APPOINTMENTS

To ensure that a child with special needs is allotted enough time for history and physical examination, the appointment cannot be the standard 20 to 30 minutes; often it will be 1 hour or more. Being in a group practice allows for other children to be seen while you are seeing your patients with special needs. Office staff should know who requires more time so scheduling can be arranged to provide care for all the children seen in the office on any particular day. Individual practitioners may need to see the child early in the morning, end of the day, or into lunchtime to allot appropriate time. Your partners should understand that these children need more time, and financial concerns should not be a reason to deny care. Too many pediatricians won’t care for these children due to lack of reimbursement. Billing for routine care and chronic conditions at the same visit increases reimbursement, and is allowable with insurance carriers. This should be discussed with your billing company, at billing seminars, or with your contracted insurance carriers.

Assessing History

As with every patient, but especially the child with special needs, interact with the person. Making eye contact or simply shaking hands with the child, and engaging them in conversation and the history taking process (when possible) is important to building a relationship with the child and the family.

Review old records when possible, and obtain a thorough history. Inquire about how old the child was at diagnosis, how the diagnosis was made, and relevant testing conducted. For young infants and toddlers, pregnancy complications should be assessed, and family history is critical.

Assessing the history by organ systems is very helpful. Start at the top with ears, eyes, nose, and throat, for example. Ask about hearing, vision, swallowing, and sleep routine (snoring, apnea, or disrupted patterns). Then progress to the chest and lungs, ask about aspiration, pneumonia, chronic lung disease, tracheotomy, and pulmonary treatments for airway management. Cardiac issues should be reviewed (congenital heart disease, arrhythmia, pacemakers, or surgery). Gastrointestinal issues such as gastroesophageal reflux (GERD), tube feedings, or surgeries are important. Inquire about bowel habits and constipation, which can be a health issue in many people with special needs. Urinary continence, need for bladder catheterization, urinary tract infections, or renal diseases are important to know about as well. Discuss ambulation and orthopedic-related issues such as surgery for tendon releases or hip subluxation, fractures due to osteopenia, and screening for scoliosis. With lack of ambulation, positioning is important.
Twenty-five percent of girls and therefore any concerns regarding the risk/occurrence of abuse. Does the home have smoke and carbon monoxide detectors, ramps for emergency exit, and appropriate car restraints and transportation. Fall prevention (lifts and physical assistance) and risks (carpeting and stairs) should be discussed along with any other medical equipment or adaption. The family’s local power company should be aware that there are special needs in the household so that power can be restored promptly in case of an outage. Backup equipment should be accessible and functioning.

Safety

Does the home have smoke and carbon monoxide detectors, ramps for emergency exit, and appropriate car restraints and transportation. Fall prevention (lifts and physical assistance) and risks (carpeting and stairs) should be discussed along with any other medical equipment or adaption. The family’s local power company should be aware that there are special needs in the household so that power can be restored promptly in case of an outage. Backup equipment should be accessible and functioning. Spare tracheotomy tubes, if used, should be easily accessible.

All medications and any relevant safety issues should be reviewed. Discuss with the family the list of specialists, and determine who is responsible for each specific condition, medication, and safety parameters. Also be sure to ask the parent and child if there are any safety-related issues that were not discussed. This way, both the parent and child feel that all issues have been addressed.

Physical Examination

Vital signs including height and weight should be obtained. Smaller children and those who can be held by a parent should be placed on a scale if possible. For adult-sized children who do not ambulate, either a special scale should be used or recent weights should be obtained from a previous setting. The child should be minimally clothed to observe for skin breakdown, bruising, or rashes. There should be particular attention to the areas affected by chronic disease. Describe developmental skills, neurologic functionality, muscle tone, spasticity, dysmorphic features, in-dwelling equipment (gastrostomy button, tracheotomy tube), as well as the status of the heart, lungs, and abdomen. Is the child wearing or using equipment such as an ankle foot orthosis, ventilator-dependent, fitted with pulse oximetry, hearing aids, or glasses. The key thing here is describing what is seen; the physician does not have to remember what cranial nerve causes a facial palsy, but should document the observation.

Children with special needs require the same basic screening as children without disability. Hearing and vision screening, periodic complete blood count testing, lead screening, and cholesterol monitoring should be done at the appropriate age. Dental care is also an important part of assessments because good oral hygiene is critical to overall health; medications, GERD, and poor swallowing all contribute to dental risk. Some children with special needs will require anesthesia for routine dental care, and if it can be coordinated with other surgeries that would be beneficial. Special needs children with chronic respiratory or heart conditions are candidates for pneumococcal conjugate vaccine 13 and 23. Children should also receive an annual influenza vaccine. Vaccine administration often can occur per recommended American Academy of Pediatrics/Centers for Disease Control and Prevention scheduling; however, this should be evaluated on an individual basis as the child’s disease(s), condition(s), or medications may necessitate an altered schedule.

Children with a disability are at a 3-fold greater risk of abuse or maltreatment than other children without a disability. Sixty-five percent of girls and 17% of boys will be sexually abused before age 18 years in the general population. Therefore, any concerns regarding sexual or physical abuse are important to discuss with the child or adolescent, as well as with the family or guardian. If deemed necessary after examination, human papillomavirus virus vaccine should be administered and birth control should

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<tr>
<th>TABLE 1. Common Terms and Conditions in the Care of Children with Special Needs</th>
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<tr>
<td>Thoracolumbosacral orthosis for spine stability (TLSO)</td>
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<tr>
<td>Ankle foot orthosis for ankle foot stability (AFO)</td>
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<tr>
<td>Supramalleolar orthosis for foot stability (SMO)</td>
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<tr>
<td>Autism spectrum disorder (ASD)</td>
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<tr>
<td>Gastrostomy tube/button (GT/B)</td>
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<tr>
<td>Jejunostomy tube (JT)</td>
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<tr>
<td>Intrapulmonary percussive ventilation (IPV; manages secretions in the treatment and prevention of pulmonary disease)</td>
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<tr>
<td>Cough-assist treatment (a device that delivers air to the lungs then reverses flow to withdraw secretions and improve the natural cough effectiveness)</td>
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<tr>
<td>Vest treatment (mechanical vest applied to provide vibrations to the thorax and mobilize secretions)</td>
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be discussed to prevent unwanted pregnancy. Oral contraceptives and intrauterine devices are most commonly used in the reproductive-age group. Oral contraceptives help with management of menses, and could be important for the hygiene of girls with special needs.

COORDINATION OF CARE

As the pediatrician caring for the child with special needs, a major responsibility is coordination of care. Aside from the family, the pediatrician should know the child’s health best, and use it to pull together the information from the specialists. Having an electronic medical record (EMR), which the entire medical team can use, allows for a central point of information and easy access. Some EMRs have tablet or smartphone applications, making access to information almost immediate. If a coordinated EMR is not available, use written reports from specialists to track up-to-date information. Knowing the capabilities of your local hospital also ensures appropriate use of the facility, and whether other hospitals in your locale or region are necessary.

Telemedicine is another means to communicate with families. Text messaging or emailing about changes in health status or treatment is efficient and, in many ways, keeps the child home and out of the hospital. It is important to set guidelines with families on expectation of response time and to have a good trustful, working relationship with the family so that, if deterioration occurs, medical attention will be sought. Having the family and child with special needs see one physician in the office regularly allows for familiarity and development of this working relationship.

Caring for children with chronic conditions means you also should advocate for the child’s (and the family’s) needs. Writing letters to obtain services (home nursing, equipment, therapies), disputing insurance claims/rejections, obtaining appropriate but denied medications, and signing school forms come as part of the job.

Guardianship should be discussed with families as the child approaches age 18 years (begin talking with the family at age 16 or 17 years), so the necessary forms can be completed on time. The Health Insurance Portability and Accountability Act is real, and many people with special needs cannot make their own decisions at age 18 years and beyond.

Transition to adult care should also be planned starting in adolescence or early adulthood. As pediatricians, we tend to not let go. Finding adult physicians in the community who work with this population is difficult. Concerns among internists are understanding the medical conditions of the young adult, continued family involvement in care, the patient’s developmental and social needs, reimbursement costs from insurance and Medicaid for office visits, and how the adult world of medicine will cover services such as at-home nursing care and therapies. As they reach age 21 years and older, they should move to the “adult” world in terms of physician care.

End-of-Life Planning

For some children with special needs, discussion of end-of-life issues may be necessary. These should be individualized to each child, and based on diagnoses, prognosis, and complications of the underlying disorders. Spiritual and cultural considerations must also be made. A family’s experiences and culture/religious beliefs must be considered so that the family, child, and medical team all have an agreeable end-of-life plan. The Patient Protection and Affordable Care Act Section 230 now allows families to continue cure-oriented treatment and receive hospice care at the same time without having to sacrifice one for the other.

Other Resources

Additionally, referring the family to financial planning resources, without giving financial advice, may be beneficial. There are laws pending that allow for saving for children with special needs similar to creating a college fund (529A or ABLE [Achieve a Better Life Experience] account). As parents themselves get older, strenuous physical care for their children may no longer be safe or possible. Discussion regarding congregate care settings such as skilled nursing facilities, intermediate care facilities, residential settings, and group home living should be offered, which can bring a sense of relief to the parent.

FINAL THOUGHTS

Children with special needs contribute immensely to their community, school, and family through their strengths and dignity. They teach us a lot about quality of life. Caring for these children is a rewarding part of pediatrics. Having a better understanding of their overall care ensures that a safe medical-home environment can be set up to meet their day-to-day medical needs.

REFERENCES