Introduction

The Need for Day Treatment Programs

Out-of-home medical day treatment is home care that is provided at the parents’ request at a site other than the child’s home. Some parents request this out-of-home day treatment for long periods, while others request it for weekends or regularly scheduled respite days. Parents want flexibility in scheduling and arrival and departure times and a quality staff.

Many of the following factors motivate parents to search for out-of-home medical day treatment:

- Parents tire from constant traffic of nurses, respiratory therapists, and durable medical equipment companies in their home.
- Parents and siblings want and need regularly scheduled time alone.
- Parents must return to work or school to improve the economic status of their family.
- Parents want their child to have some time away from home to participate in socialization experiences with children with and without disabilities.
- Parents want their child in an early childhood education and child care environment.
- Center-based care is a cost-effective alternative to in-home skilled nursing care and institutional care.

There are several exemplary programs nationwide that give parents access to a flexible and broad range of services. Some of these programs effectively integrate children in home care into the fabric of their communities.
Models

In the late 1980s, Prescribed Pediatric Extended Care Centers (PPECCs) were established in Florida. This innovative day health care model is physician prescribed and qualifies for insurance reimbursement. The PPECC offers skilled nursing care in a group setting, respite, and parent education. This successful model strongly influenced the second-generation model established in 1993 by the Medical University of Ohio in Toledo. In this model, the Prescribed Pediatric Center (PPC) provides skilled nursing services, early childhood education, and developmentally appropriate education in a group setting. The staff consists of certified teachers and nurses who work as a team to provide education and recreation for children from birth to 12 years of age. The PPC is located in a spacious former elementary school with outdoor play areas, a gymnasium, and an indoor sensory motor room. In addition, the PPC is located in an inclusive early childhood facility that provides supported opportunities for socialization with peers with and without disabilities in a child care program for typically developing children and is the home base for early intervention activities in that county. Nurses from the PPC provide nursing care to school-aged children in 4 multihandicapped classes operated by the Toledo Public School System. The PPC also provides before- and after-school care for many of these children, thus giving working parents the wraparound coverage they need. This model provides continuity of nursing personnel, eliminates the problem of call-offs, and is much less costly than in-home care or having one nurse per child in a classroom. Lastly, transportation time and costs are reduced to a minimum for the child is wheeled, is carried, or walks from one classroom to another. Parents are very grateful for the seamless way these 2 agencies work together.

In 1999 Respite House, Inc., became a reality in Illinois. A group of committed parents and professionals changed the way respite care was defined in the Illinois state statute by recognizing respite care as a medical necessity for children who are medically fragile. The term medically fragile was defined as a person who requires medical technology to sustain life and prevent death or further injury. Respite House was a medical respite care facility designed to give parents of children with complex needs a break from around-the-clock worrying and caregiving. Parents could drop off their children for as long as 14 days, yet still have the confidence
that their child was being well cared for. While still providing respite, the center is offering a new service—transitional care for fragile children after a major hospital stay, before they return home. Now called the Coordinating Action for Children’s Health (CoACH) House, children are discharged from the hospital and the CoACH House provides nursing services in a homelike environment where parents benefit from nurse education. There is a maximum of 10 children at one time. Transitional training (ie, hospital-to-home training) is provided for families whose children are being discharged from the hospital and for foster families interested in fostering a child who is medically fragile. Child life services and education also are provided. Each of these programs provides year-round services with flexible scheduling for parents’ convenience.

**Program Design and Services**

► **Eligibility and Admissions**

Referrals to medical day treatment and respite programs can be made by the family, school personnel, and child’s medical home. Parents should be made aware of this resource early in the course of the child’s complex illness. If the child is dependent on a ventilator, has a tracheostomy, or has other complex health needs, the medical home or managing pediatric subspecialist should originate the referral. Referral during hospitalization facilitates collaborative planning and is appreciated by families. All parents should be informed about these resources even though many will say they are not interested. But as time goes on many parents realize they must have qualified help and it is not being disloyal to their child—rather, it is being responsible to their family. All parents need regular periods off from parenting and parents of children with complex health problems need it more than most others. Respite and coordinated day treatment help renew a family’s well-being.

► **Assessment**

A written individual health plan (IHP) for the child and family should be done prior to contracting for services. In some situations, the assessment is done by a hospital-based team and is shared and discussed with the facility staff. Pediatricians who personally communicate with the program staff
help their patients get the best and most appropriate staff support. The following are key elements of the IHP:
• Brief health history and immunizations
• Special health care needs
• Medications
• Diet and nutrition
• Transportation
• Equipment
• Possible problems and interventions

The IHP should be written by the managing pediatric staff and signed by one physician and include a phone number, fax number, and mailing address. This initial assessment should indicate how often and by whom the identified services will be provided. If the facility generally does not provide the services, contracting or arranging with the appropriate professional should be detailed.

► Medical Role

Physicians have a major role in patient care, but a limited role in home care. Some pediatricians do remain involved in home care to monitor the quality of home care provided, coordinate the child’s care and referrals that are made, ensure that the family and medical home continue to work together, advocate for the child and family as problems arise, and confirm that the reordering of home care services continues to meet the needs of child and family.

► Nursing Care

Nursing care for children in a medical day treatment program is ordered by each child’s pediatrician or primary care physician. The following is general care for all children in the program:
• Temperature, pulse, respirations daily
• Pulse oximetry daily, if appropriate
• Weight weekly
• Cardiopulmonary assessment daily
• Gastrointestinal assessment daily
• Neurologic assessment daily
• General assessment (skin color, temperature, turgor)
• Mouth care twice daily and as needed
• Skin care as needed
• Activities as appropriate

Universal precautions are practiced because of the vulnerable nature of many of the children.

All food, medications, supplies, and equipment specific to each child are provided by the child’s family. Backup supplies are provided by the center, as well as emergency equipment (eg, oxygen, suction). A variety of general activity equipment is available, including standers, corner chairs, slant pillows, side-liers, and a water bed.

**Special Therapies**

Important participants in a child’s care team may include occupational, speech and language, and physical therapists. Ideally, each therapist will have excellent professional relationships with each home care nurse. Such relationships will result in the therapist advising the nurse on activities to reinforce, the nurse discussing with the therapist concerns and questions about the patient, and a transdisciplinary relationship that strengthens the quality and unique implementation of each child’s care plan.

**Developmental Interventions**

Safety and medical care are the primary concerns in caring for the child with special health care needs. However, accepting the role of caregiver includes attending to the developmental needs of the child and integrating developmental services with the health care of the child. Staffing, consultation with local early intervention and special education programs, and an overall philosophy of developmentally appropriate care are the basis for high-quality care.

**Family Support and Education**

Public Law 105-17, the Individuals with Disabilities Education Act (IDEA) Amendments of 1997, established the early intervention program for infants and toddlers with disabilities, including free and appropriate public education for children with disabilities from ages 3 to 21 years. Children who are medically fragile and at risk for developmental delay may be eligible for IDEA services. Early intervention services may include service coordination; transition planning; special instruction for the child; support and training for the child’s family; therapies such as occupational,
physical, and speech; audiology; and assistive technology. Referrals are made through a state central resource directory or a local early intervention contact. Special education and related services (eg, speech therapy, occupational therapy, assistive technology) are provided to eligible children from age 3 years. Referrals are made to the local education agency (ie, public school) where the child resides.

Every state and jurisdiction is responsible for providing early intervention or special educational services for eligible children with disabilities. Although IDEA provides statutory and regulatory guidance for these services, states have discretion in establishing some aspects of services, including eligibility definitions. Service delivery mechanisms vary from state to state. Because many children served in medical day care may be eligible for IDEA services, staff should contact the state lead agency for early intervention and the local education agency (public school) to determine the policies and procedures within the community.

If the child qualifies for special education or early intervention services under the state’s definition, all IDEA regulations apply. For example, a child younger than 3 years who is medically fragile would have all services described on an individual family service plan (IFSP); children from age 3 years would have an individual education plan (IEP). These plans require that appropriate and individualized evaluations, assessments, and goals are established for enhancing the development of the child. Individual family service plans and IEPs are developed in conjunction with a multidisciplinary team and with the active involvement and consent of the family. The family’s concerns, priorities, and resources, as well as the fragility of the child’s medical condition, should be taken into account in the writing of these plans.

Children from birth to 3 years of age with an IFSP are also entitled to a service coordinator, who serves as the primary contact for all intervention and care provided to the child and assists the family in obtaining needed services and supports. Although there are several public programs serving
children with disabilities, it often is difficult for families to locate or access these programs, services may not be available or convenient, or the child’s needs may not be completely met by the program. The service coordinator can help families determine which programs might be available. For children who are medically fragile, frequently it makes sense for the initial service coordinator to be the child’s primary care nurse. The nurse then can ensure that developmental interventions are coordinated with nursing and medical care. The nurse serves as a liaison with the family, intervention team, and physician.

For services to infants and toddlers, eligibility criteria and definitions vary from state to state. Under Part C of IDEA (Programs for Infants and Toddlers with Disabilities), states must provide services to children younger than 3 years who are experiencing developmental delays or who have a diagnosed physical or mental condition that has a high probability of resulting in developmental delay. States also may choose to provide early intervention services to children considered at risk of experiencing a substantial developmental delay if early intervention services were not provided.

Children aged 3 to 21 years who are medically fragile may qualify for special educational and related services. For the purposes of eligibility, a child with a disability is defined as a child with mental retardation, hearing impairment, speech and language impairments, visual impairments, severe emotional disturbances, orthopedic impairments, autism, traumatic brain injury, other health impairments, or specific learning disabilities and who, by reason thereof, needs special education and related services. For children aged 3 through 9 years, the term child with a disability may include a child experiencing a developmental delay (in cognitive, physical, adaptive, social, emotional, or communication areas) who needs special education and related services.

**Transition Planning**

Children who are medically fragile will experience many changes in service setting, providers, routines, and procedures. Some of the most significant changes are those involving a change in location, including the transition from hospital (acute care) to home; transition from home care to a specialty child care center; and ultimately, transition into a natural
Guidelines for pediatric Home Health care environment (eg, typical child care, early childhood program, school).
All transitions must be planned, with attention given to the strengths and needs of the child and family, so the process allows the child’s medical and developmental care to continue without interruption. The goal of transition planning is to ensure that the process of change is as smooth as possible; stress on the child and the family is kept to a minimum. The child’s family, primary health care providers, and local program or school staff should carefully plan transition from home care into community-based medical day treatment programs.

Identifying a transition team can help to identify appropriate community resources including family support, transportation, respite care, early intervention, and educational resources. A nurse who is familiar with the child should be present during the assessment and initial implementation of therapies to monitor for signs or symptoms of stress or intolerance of developmental interventions. Persons conducting the assessments should be familiar with children who are medically fragile. The rule of thumb for assessments and developmental therapies is to limit the number of people handling the child. Some intervention teams may be skilled in the transdisciplinary approach, where the team provides consultation to one or two direct service providers. Planning, observation, and flexibility should be guiding principles for the intervention team.

**Personnel/Staffing**

A medical day treatment program is staffed by experienced nurses with a pediatric background. At all times, a Pediatric Advanced Life Support–certified registered nurse (RN) with pediatric ventilator experience is on site. Each child is assigned a primary nurse. The nurse-child ratio is determined by the acuity level of each child; average nurse-child ratio per experience is 1:3. An RN is on site while the center is open and licensed practical nurses serve as supplemental staff to maintain the nurse-child ratio. Licensed practical nurses also are used as transport nurses for children who require a medical professional while being transported from home to the day treatment program and back. The 3 acuity levels of care are listed in Table 34-1.
Program Management

★ Licensure and Related Policies

Requirements for licensure of a medical day treatment program vary from state to state. State rules and regulations governing the particular owner type of the program (eg, acute care facility or health system, freestanding home health agency, extended care facility, school) also may affect the need or type of licensure required for the program. Classification or certification as a child care program, extension of the educational system, subacute center, or a combination thereof will dictate the need for or advantages of further certifications or accreditations, in addition to baseline requirements.

Each licensure type and certification or accreditation is accompanied by its own set of requirements for standards, outcome measures, reporting, record keeping, and periodic survey. The benefits of additional accreditations of the program should be weighed carefully against the cost as well as the additional staff needed to maintain compliance.
with standards. Accreditations through organizations such as the Joint Commission, Community Health Accreditation Program, and other national accrediting bodies may carry significant financial obligations and possible imposition of sanctions, in addition to the outcome-based consumer and provider benefits.

**Medical Records and Record Keeping**

Maintaining detailed individual medical record charts on a daily basis is critical to mapping the progress and measuring outcomes in accordance with stated, integrated clinical and developmental goals. Each chart should contain the following information:

- Signed physician orders for care
- A complete and thorough physical and developmental assessment updated at regular intervals
- Daily signed charting of the child’s activity and performance of nursing tasks as related to the orders
- All collaborative intervention notes or reports that focus on the medical and developmental needs of the child
- Subsequent verbal physician orders
- Complete medication profile and subsequent updates
- Demographic, economic, environmental, and psychosocial data

Documentation in the child’s chart must address performance of the physician’s prescribed orders for medical care and the educational objectives identified by an early intervention specialist, early childhood teachers, or a therapist. Typical pediatric-specific home health or acute care facility charting forms should be modified to include the developmental components typically found in the documentation used by an early intervention team or mental retardation/developmental disabilities (MR/DD) system. Pertinent goals established within an IEP or IFSP also should be incorporated into the day treatment documentation. Embedding the developmental goals into the day treatment plan establishes a more complete, thorough picture of a child’s total progress. The collaboration of the nursing and early intervention team to draft such documentation also fosters a closer team approach to delivery of family-focused care and the successful accomplishment of goals.
Each chart is a confidential record that contains sensitive information, including a child’s medical condition, social and home environment concerns, and custody issues. Great care must be given to securing records to ensure limited, authorized access. Parental or guardian consent for publication of any child’s information must be obtained and placed in the chart or other secure place.

Physical and Learning Environment

Medical day treatment centers must provide opportunities for cognitive, language, social, emotional, adaptive, and physical development. Ideally, these learning opportunities include interaction with typically developing children, because children who are medically fragile have conditions that may stabilize or improve over time. Placement in a specialized child care setting with medical and nursing support should be considered transitional, not permanent. Developmental interventions and nursing care prepare the child for more natural, less restrictive settings in the future.

During the time that a child who is medically fragile is unstable, it is unlikely the child will be fully included in child care or other community programs. However, the ultimate goal of the IEP or IFSP should be to provide the child with as natural a learning experience as possible. For an infant, that might mean interaction with a small number of caring, consistent caregivers. For a young child, there might be opportunities for interaction with other children. For older children, there will be typical routines and activities. There may need to be modifications in toys, play equipment, play areas, and learning environments. Consultation with early childhood programs (eg, Head Start, Early Head Start) and local school personnel will help to create a comprehensive program of health and educational services.

Quality Assurance and Accountability

A quality or performance improvement plan that identifies the mission, objectives, and performance of the program should be firmly established. Once developed, this plan should drive the collection of clinical and developmental data that support the day treatment role.
Clinical outcomes and developmental milestones should be measurable with the clinical chart documentation structured to capture and follow a child’s progress. Standard clinical quality indicators include
- Efficacy of the procedures or treatments
- Appropriateness of the procedures or treatments
- Availability of needed procedures or treatments
- Timeliness with which needed procedures and treatments are provided
- Effectiveness with which procedures and treatments are provided
- Continuity of the services provided
- Safety of the client to whom the services are provided
- Efficiency with which the services are provided
- Respect and caring with which the services are provided

Additionally, measurement standards to benchmark a child’s developmental progress against child-specific expected goals must be added. Professional developmental assessment tools that measure the developmental progress from birth through 5 years of age can assist in the periodic consistency with which data are captured.

**Financing**

**Medicaid Waivers**

Each state’s implementation of federal funding under a Medicaid medically fragile waiver or extended care reimbursement model program will vary. Most waiver programs are administered by the respective state’s department of human services (health or similar division). While application needs to be made to the state, information about application for providership, eligibility criteria, and payment and billing procedures should be available through each local county department of human services.

Waiver programs are designed to provide home- and community-based services to patients who have a chronic, unstable medical condition requiring the skills of an RN on a daily basis to detect and evaluate the need for possible treatment modification or for instituting other procedures. These patients otherwise would require long-term care, hospitalization, and potentially out-of-community placement at a residential facility designed to accommodate such cases. A cap rate for expenditures per participant per
month or annually usually is established by each state. This cap rate may include all authorized medical and health–related expenses incurred by the child. Payment to providers normally is set at one statewide maximum rate per service type. State waiver programs may cover services to include private duty (hourly) nursing, respite care, home medical equipment and supplies, adaptive or assistive devices, therapy services, and social work or counseling. Patients who have been authorized to receive services under a state waiver program normally require the highest level or combination of services. Each child has an assigned RN or social work case manager who is responsible for the coordination of collective services each child receives and awards hours of nursing services in the day treatment or home setting.

► Public and Private Health Insurance

Alternative public funding sources, in addition to the Medicaid and Medicaid waiver programs, will vary from state to state. Providers should investigate eligibility for providership under all programs administered through the health and human services state department, as well as the MR/DD and state educational system. A provider of medical day treatment may be successful in obtaining financial support for school-aged children who cannot attend a typical classroom. Contact with the local county board of MR/DD should assist in accessing alternative funding streams under the Medicaid system.

Because of the high cost and long-term nature of many of these cases, the private insurance industry has been a reluctant payer source. A strong case can be made for private insurance case management and authorization of payment for services rendered at a medical day treatment program. The delivery option provides a safe environment, is cost-effective compared with the institutional inpatient setting or seclusion of home care, and has evidence of marked decreased use of emergency departments and subsequent hospitalization. The collaborative efforts of all providers of care under one roof also increases the continuity of care and case coordination, thereby decreasing the number of appointments with different professionals; puts a halt to repeated invasions of family privacy; and saves time and energy.
Title V and Children With Special Health Care Needs
Title V programs of the Maternal and Child Health Bureau and programs for children with special health care needs have federal or state resources. States have choices as to how these funds are allocated. Some states fund care coordination for children with special health care needs. However, few state Title V programs provide or fund home care services. Grant funding often is available for innovative activities but does not support ongoing reimbursement for home care services.

Contracts With Public Agencies
Financial support on a contracted basis for services rendered in the medical day treatment setting to like clients is available by establishing working relationships with area school systems, county boards for MR/DD, county boards for children’s services, and other collaborative agency network support programs that provide services to families and children with special needs. Often, pooled community funding support programs are available and can be found by contacting the local United Way. Because of the stringent fiscal funding cycles of many county agencies, budget submission deadlines and application dates must be adhered to.

Private Philanthropy
The financial viability, growth, and expansion of a medical day treatment program and the services it provides will be related directly to the volume of philanthropic dollars generated to support it on an ongoing basis. Because of the cap rates, lifetime benefit maximums, and the intensive and extensive nature of skilled and social interventions needed for these children and their families, cost for services often exceeds reimbursement, leaving a gap to be filled by charitable dollars. In addition to funding support for direct care, grants for new program development and research, tuition assistance, private endowment, and deferred giving options will provide longevity to the financial integrity of the program and increase the options available to all families regardless of their ability to pay. Funding available through locally based foundations, local branches of national foundations, hospital systems and corporate foundations, and the local United Way are excellent options to pursue.
Partnerships

**Role of the Advisory Board**

Development of a diverse, well-rounded advisory board or committee serves several key purposes for successful development of a medical day treatment program. An integrated team of medical professionals, educators, parents of children with special needs, third-party payer representatives, and community, county, and state representatives of programs that serve or coordinate services for the special needs population can be invaluable in establishing a firm strategic base of knowledge and information sharing. The advisory board may serve in various capacities depending on the structure of the program owner, business operation, and established board or committee goals. Goals of the advisory board include but may not be limited to the following:

- Identifying families of children with special needs who may be appropriate for the day treatment program
- Creating a nonthreatening mechanism for the services of the day treatment program to be introduced to those families
- Serving as a means for dissemination of information on legislative-related activities and a forum for ongoing and acquiring support as needed
- Identifying and communicating with possible funding sources that may support payment for or expansion of medical day treatment services or enable research opportunities
- Working in conjunction with appropriate resources to provide a uniform and consistent message that will increase the knowledge level of the general public about how children with special needs and their families are similar to all other children and families, yet also face unique challenges and demands
- Educating health insurance companies to acknowledge and meet the needs of the family and child with special needs

The following community agency members are recommended for inclusion on an advisory board:

- Local pediatricians serving children who are medically complex
- County early intervention representatives
- County MR/DD board
• County children’s services board representatives
• Physical, occupational, and speech therapists
• Area children’s hospital and academic department of pediatrics
• Local special education school board representation
• Special education teachers
• Area philanthropy specialists
• Representation from any other agency whose focus of service is on the population of children with special needs
• Local organization of parents of children with special health care needs—with at least one parent who currently uses the program, if possible

Early Intervention, Early Care, and Education Programs

Forming relationships with organizations that provide early care and education promotes community-wide awareness and commitment to serve children with complex health problems. Head Start and public preschools can be helpful as a curriculum resource and as a resource for care when transition is appropriate, and may be of help financially with some children.

Hospitals, Other Health Care Providers, Colleges, and Universities

Strong relationships with the major providers of acute pediatric care promote timely referrals, cooperation between hospital nursing staff and center-based home health staff, and open lines of communication for all future needs. Out-of-home medical day treatment centers are excellent sites for supervised clinical training of medical students, pediatric and rehabilitation residents, nurses, allied health students, and early childhood educators. Because children attend the program over a long period of time, the experience also provides excellent opportunities to teach best practices for pediatricians who are the medical home for patients with high-technology needs or chronic complex health issues.

Summary

Out-of-home medical day treatment programs provide respite for the family. The central role of the family in the ongoing care of the child is supported when center-based medical day treatment programs are acces-
Out-of-home child care and medical day treatment programs are possible and operated by a quality nursing staff in a natural environment (child care or school) that promotes socialization with peers with and without disabilities and developmentally appropriate education. Because the number of children with chronic diseases that may be appropriate for home care is increasing, this specialized medical day treatment should be of interest to all pediatricians and considered when developing the continuance of care options for children who are medically fragile. This is a cost-effective alternative to pediatric home care delivered exclusively in the home.

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Shackelford J. State and jurisdictional eligibility definitions for infants and toddlers with disabilities under IDEA. NECTAS Notes. April 2000:1–14
Resources

Illinois Department of Public Health Office of Health Care Regulation
525 W Jefferson St
5th Floor
Springfield, IL 62761-0001
William Bell
217/782-2913
www.idph.state.il.us/home.htm

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