

Care of The Child With Disabilities _

Knowledge

Demographics

3% of American children have chronic illness and physical handicaps

2% have severe developmental disabilities

Examples of medical problems encountered

cerebral palsy, neural tube defects, congenital anomalies, genetic problems

Important to make a specific diagnosis when possible; allows specific treatment

may need genetic counseling

allows for anticipation of known natural history

Also helpful to know when to stop pursuing a diagnosis; cuts down on expense (both fiscal and emotional)

stops "doctor shopping" by parents

allows concentration on management issues

No matter the diagnosis ALL children with chronic illness

Require comprehensive treatment from many providers

Represent a burden of care on families which may generate major psychological and social needs

Have the same needs for school, recreation, and vocation

Training as non-disabled

Usually require a multidisciplinary team with a

Primary care physician to coordinate the care and

Make sure that the family is receiving consistent

Information and management

Care should follow the principles outlined by the AAP in

Project Bridge, i.e., be:

Family focused

Developmentally oriented

Coordinated with school and other services

Accompanied by patient and parent education

Attentive to environment

Preventing secondary disabilities

The goal of care should be: fitting into society, e.g.,

Mobility

Activities of daily living

Communication

Academic performance (students with disabilities are 50% more likely to drop out of school than other students)

Caregivers should always keep in mind the effect of illness on the family, e.g., sibling reaction, financial and marital stress

Financial coverage

Crippled Children's Services/Children with Special Health Care Needs

SSI/Disabled Children's Program

Maternal and Child Health Block Grants

Agencies involved

Developmental Disabilities Planning Office

Department of Health-birth-3yrs

Department of Education-school age

Vocational Rehabilitation/Department of Mental Health adults

Skills

Ability to establish primary medical diagnosis, the involvement of other organ systems, and the genetic implications

Ability to deal with associated medical concerns, e.g., facility with problem oriented medical approach to address multiple complex medical problems

Special expertise in pain management and technology dependency

Ability to assess developmental status

what is child's IQ?

what is child's functional capacity?

is child suffering from a progressive or degenerative illness or is the problem static?

Emphasis on outpatient management as much as possible
plan ahead for elective hospitalization to minimize family disruption

Facility with maintaining a "problem list" and a medical/procedure list and review of it with parents and caregivers periodically

Ability to focus on the "whole child" including psychological, social, and educational issues

Ability to work with the total family

deal with questions, fears, defense mechanism

include them in decision making

Ability to work in a team -- "shared management approach"

Don't overlook well child issues: immunization, screening, anticipatory guidance

Attitudes

Provider must be willing to accept care NOT cure

Despite the inability to cure, provider should have long term commitment to confining the disability
Willingness to deal with parental feelings of guilt and to accept the burden of their anger
Recognize child's fear of pain, death, abandonment, "being different"

Barriers

Time constraints on physician to address multitude of needs
Difficulty of working with emotional issues that arise in families who have a child with a chronic illness
Administrative: burden of paperwork involved in the care of these children
Medically, providers may not feel as "in control" when there is not a definitive diagnosis, or a single "correct" management
Difficulty of staying current on highly specialized and sometimes rare conditions
Financially, problems with 3rd party reimbursement for "conference time"; need to work out contracts with residential care facilities
Emotional discomfort of working with chronic illness, e.g., feelings of frustration, helplessness
Ethical issues of certain interventions in terms of usefulness in the total picture

Advocacy

PL 94-142 and PL 99-457 guarantees the child with disabilities the right to an education " in the least restrictive environment" but the provider should assure this by:
communicating with school personnel
accompanying parents to Committee for the Handicapped Meetings
reviewing Child's Individualized Education Plan (IEP) and making sure the Health Care Plan is incorporated into the IEP.

References

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