

Implications of the Population Definition

Introduction

The way the population of technology-dependent children is defined and enumerated has clear implications for the costs to third-party payers of paying for care, and the access of these children to different care alternatives. The broader the definition, the larger the number of children who may become eligible for special benefits. Providing enhanced insurance coverage for technology-dependent children may itself lead to an increase in the size of the population, through encouragement of more aggressive medical practices.

The definition of technology dependence presented in Chapter 2 was developed for the purpose of enumerating the population, not for describing it for insurance or program eligibility purposes. These two definitional purposes overlap to some extent, but they can also conflict. The pragmatic, data-based definition applied in this technical memorandum would be inappropriate if applied in a program context without other considerations. To be applied appropriately to eligibility, a definition of technology dependence must take into consideration the following questions:

- Does the definition include all children who would reasonably be considered to be technology dependent?
- Is the definition flexible, or would it need to be revised frequently to accommodate new groups of deserving children?
- Can the definition identify children with similar needs for health care, so that they can receive the same level of benefits (horizontal equity); and can it distinguish those with greater need from those with lesser need (vertical equity)?
- Can the definition distinguish between children for whom home care is less expensive than institutional care from those for whom it is more expensive (possibly because the child would not be institutionalized even in the absence of home care benefits)?
- Is the definition compatible with distinguishing children for whom home or community-based care is feasible and desirable, and can it provide a basis for estimating the cost of services provided in these environments?

Three potential specific approaches to identifying the population are to use: 1) diagnosis, 2) functional limitation, or 3) medical services needed. These approaches are not necessarily mutually exclusive, but their benefits and drawbacks can be discussed separately from one another.

Three Alternative Approaches

Definition Based on Diagnoses

Diagnoses could be used as a basis for identifying children as technology dependent, an approach that has two attractions. First, in most cases diagnoses provide distinct and verifiable information. Second, diagnostic data on hospitalized patients are regularly collected and analyzed on a national basis.¹ A definition of technology dependence based on diagnosis could be specific (e. g., bronchopulmonary dysplasia) or broad (e.g., any chronic lung disease).

There are a number of serious problems with using this approach. First, there is not a one-to-one correspondence between diagnoses and the need for long-term intensive nursing care. Table 26 lists a few of the many diseases (some of them very rare) that can lead to life-sustaining dependence on respiratory or nutritional support. Maintaining a comprehensive list might be very difficult, preventing some technology-dependent children from being included. Also, only a small proportion of the children with these diseases require prolonged technology supports. For example, of children with muscular dystrophy or cystic fibrosis, only those in the later stages require ventilators or even less intensive respiratory support such as frequent suctioning and oxygen (4,79). Thus, any definition that includes diagnostic criteria must rely heavily on other criteria as well.

Defining the population based on broader categories of diagnoses or disorders would be considerably less cumbersome but correspondingly less specific. It, too, would produce categories that are larger, probably many times larger, than the population of children that is usually institutionalized and is dependent on life-sustaining medical devices.

Definition Based on Functional Limitation

Identifying disabled people, particularly the elderly, according to their functional limitations and their ability to carry out certain activities of daily living has been common for some time. Activity limitation questionnaires have been used in surveys to provide na-

¹Diagnoses are coded onto hospital discharge abstracts, according to the conventions of the International Classification of Diseases, 9th Revision, Clinical Modification (ICD-9-CM) coding system. These codes and other information from discharge abstracts are then maintained, summarized, and analyzed by a number of different government and private organizations.

Table 26.—Some Conditions That Can Lead to Dependence on Respiratory or Nutritional Support

Conditions that can lead to dependence on respiratory support:

brainstem aneurysm
 bronchopulmonary dysplasia
 central hypoventilation syndrome (Ondine's curse)
 congenital heart disease
 cystic fibrosis
 Ellis-van Creveld syndrome
 encephalitis
 interrupted phrenic nerves
 multiple sclerosis
 muscular dystrophy
 myelodysplasia
 near-drowning
 nemaline rod myopathy
 neonatal asphyxia
 Pierre-Robin syndrome
 Pompe's disease
 radiation lung damage
 severe head injury
 spinal muscular atrophy
 subglottic stenosis
 upper spinal cord injury
 Werdnig-Hoffman disease

Conditions that can lead to dependence on nutritional support:

Alagille's syndrome
 chronic diarrhea
 congenital bowel defect
 cystic fibrosis
 failure to thrive
 inflammatory bowel disease
 ischemic bowel disease
 liver disease
 milk/soy protein intolerance
 motility disorder
 necrotizing enterocolitis
 neoplasms
 neurological disorders of swallowing
 radiation enteritis

NOTE These diagnoses constitute only a partial list of conditions that can lead to dependence on respiratory or nutritional support. Conditions listed here are actual diagnoses of children using these technologies, as recorded in a national nutritional support database and a summary of children served by special Title V programs in three States in 1985.

SOURCES L. Heaphey, The Oley Foundation, Albany, NY, personal communication, Aug. 21, 1986; M. J. Aitken and L. A. Aday, "Home Care for the Chronically Ill and/or Technology Assisted Child: An Evaluation Model," unpublished, November 1985.

tional estimates of disability prevalence and severity in the population (63) and in studies of resource utilization among nursing home residents (133,140,182). Scales to measure activity limitation are relatively well developed and seem to be good predictors of the intensity of required nursing and personal care services for many elderly and disabled people.

The main limitations of these scales are that each person must be assessed individually and frequently, which is time-consuming and leaves considerable discretion to the assessor; and the scales are not well

sued to identifying the specific skilled nursing services an individual may need. ^z

Another approach could be to identify children by the limitations of their normal body functions, such as eating or breathing. This approach (the one used in this technical memorandum) has intuitive appeal, because it would identify those children who use specific technologies that replace or compensate for normal body functions. The limitation of this approach is the difficulty in distinguishing levels of care needed in conjunction with the various technologies.

Definition Based on Type or Amount of Services Needed

A third approach might be to identify technology-dependent children by the type or amount of medical services they require. This might take the form of defining the population according to the need for certain nursing services, such as catheterization. Or, it might take the form of an indirect but explicit indication of level of services needed, such as prior institutionalization or time in a neonatal intensive care unit. Finally, the population might be identified by the type of long-term care plan required by its members. For example, the defined population might include children whose documented care plans specify hospice care and long-term chronic, continuous care, but not children requiring intermittent monitoring, occasional crisis care, or post-acute, recuperative care.

Considerations in Applying the Definition

Within the group of children identified as technology dependent, there will exist considerable variation in health and social needs. Ideally, an appropriate definition should be able to be applied in such a way that differences in need among children can be discerned, with appropriate differences in benefits provided to them. For example, two children might be equally ventilator dependent, but one might be able to dress and feed himself while the other cannot. This example emphasizes the value of functional assessment in applying a definition equitably.

Home care may be feasible and desirable, but not cheaper than institutional care, for some children. If

^zAlthough there is considerable experience in applying specific assessments of a person's ability to function, few of these applications have assessed any limitations in basic body functions that require nursing skills (e.g., the need for colostomy care). One survey that includes these categories is currently being conducted on children with six types of disability and chronic illness (73).

these children are to be included, the definition should have a mechanism for detecting those children for whom the medical, psychological, and developmental benefits of home care are high in relation to the additional costs of home care. This criterion again implies that the definition should include some indication of relative need and prognosis over time. A child with a long-term or terminal illness, for example, might benefit more from the psychological and social aspects of home care than a child recovering rapidly from an acute condition, and consequently it might be desirable to be able to distinguish the former child from the latter for the purposes of providing benefits.

Meeting a particular definition need not necessarily imply absolute access to a special program or set of benefits. A definition can also be thought of as a screening mechanism to most easily identify the bulk of children who would benefit from extensive individual assessment and a particular set of services. One possibility is that some fairly rigid, easily identified characteristics be used for rapid screening purposes, but that actual eligibility for benefits be dependent on the child's functional or nursing assessment score, where activity limitations, degree of independence capability, and limitations of body functions are all evaluated.