

Funding Sources

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Some states do make funds available for individuals with catastrophic disabilities, but they are in the minority. Also, in light of possible budget cuts, government funding should not be considered a stable source of long-term support.

The age of the patient must be considered when assessing federal, State or local government funding for disability management. The child with such a disability is more likely to receive funding through the state rehabilitation services office, children's medical services office or foundations established for a specific type of disability. Several states have recognized the severe and unusual expenses associated with catastrophic disabilities and do make certain funds available, but they are in the minority. In most instances, we are unable to get funding for home nursing services. Funding for equipment, supplies and medications is also limited, generally allowing for specific allotments per month that are often insufficient to cover total case needs.

Little funding beyond social security disability insurance and Medicare is available for the adult patient. Medicare does not pay for home nursing services but will pay for nursing homes if a family selects that route. Although there currently are no provisions for financing patients who require prolonged hospitalization or home care follow-up on an extensive and chronic care basis, the government is exploring catastrophic insurance programs, and such issues may change in the future.

Usually we have been able to obtain funding from the government only after applying a great deal of pressure. The old adage, "the squeaky wheel gets the grease," continues to hold true as more and more patients compete for fewer and fewer federal and state dollars. Even when patients become eligible for state or federal programs, the assistance is usually limited, often intermittent and rarely coordinated. For this reason, government funding cannot be considered stable, particularly in the face of continued budget cuts. When testifying for either the defense or the plaintiff, I recommend that only Public Law 94-142 (the mainstreaming law for handicapped children) funding can be considered a reasonable and stable source of services for that handicapped child. Although we can look to other programs for some assistance, they will not provide for all the individual's needs or even a significant percentage of those needs in a consistent or stable fashion into the future.