

Meeting Information Needs to Enhance the Community Integration of Individuals with Neuromuscular Conditions

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Despite twenty years of effort since passage of the Rehabilitation Act of 1973, individuals with disabilities continue to experience problems in accessing information and services and in receiving maximum benefits from the health care, social service, and rehabilitation systems. This inability to obtain access to information on disability-related topics may be due to geographical and physical inaccessibility, lack of knowledge by professionals, poor interagency communication, a fragmented service delivery system, resource restrictions or to the continued use of traditional patterns of service provision, especially to minority groups. There is an urgent need for access to disability related information and services, and a need to improve the quality and availability of resources, especially in the areas of attendant and home health care, respite care and financial support.

In this project the goal was to determine the extent of knowledge individuals with neuromuscular diseases had about disability-related services, to assess their specific information needs and to assess their use of disability-related information and services. The second goal, after establishing the needs of those with neuromuscular disease, was to assess the information that is available and to develop an extensive Disability Resource Guide to meet those needs.

Our survey of 566 individuals with neuromuscular diseases found that more than half of those surveyed had difficulty obtaining information on the following subjects: health care, medical research, diet and nutrition, computers, recreational opportunities, advocacy issues and durable medical equipment. Familiarity with availability of disability related services was also quite low with fewer than 40% of those surveyed familiar with Independent Living Centers, vocational rehabilitation services, transportation services for the disabled, evaluation and assessment services, and information and referral services. If individuals are not familiar with the services available to them, they are not able to access them.



To fill this information gap we developed a web based 'Resource Guide On Disability'. The guide serves two purposes: to teach individuals and their

families how to find disability-related information on the Internet and to provide one place with easy access to information on disability. This allows individuals to better manage their disability and their health, and to optimize their quality of life. Broad categories covered in the Resource Guide include 'Getting Internet Information,' 'Federal Programs and Governmental Assistance,' 'Technology, Products, and Adaptation,' 'Disability Resources,' 'Medical Resources,' 'Resources for Kids,' and 'Northern California Resources.' The guide was developed for all who are disabled, whether they have been disabled for a significant period of time or are newly disabled, for the families of those who are disabled and for those working in the health professions. The Resource Guide on Disability is currently available on the web site of the Department of Physical Medicine and Rehabilitation at UC Davis.
<http://rrtc.ucdavis.edu/pm&r/resourceguide.htm>