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Journal of Vocational Rehabilitation 10 (1998) 185-187

JOURNAL OF
*Vocational
Rehabilitation*

Editorial

Max is a young man about to exit high school who has severe spastic diplegia cerebral palsy. He has difficulty with ambulation and uses a walker (preferred) or a wheelchair for mobility. His speech is very difficult to understand and he tends to drool heavily. He requires assistance with eating, drinking and dressing, but can transfer himself to the toilet and take care of his own toileting needs. He has normal intelligence, but because of his motor problems he is often mistakenly believed to be intellectually handicapped as well.

During his elementary school years, Max attended a special school for students with handicaps, most of whom were mentally retarded. His early educational program focused on improving his communication and self-help skills, with little emphasis on academic preparation. When he was about to enter junior high, his parents objected to further placement in the special school, believing that their son would not achieve his academic potential unless he was taught the same courses as his non-handicapped peers. Although most of the other members of the IEP team disagreed that he would be 'better off' (even doubting Max's educational potential), they agreed to a trial in a regular classroom at the local junior high school.

Max's school system had participated in mainstreaming few children with severe handicaps, so Max's initial junior high experiences were far from ideal. Little time was spent preparing him, the teachers and staff, and the other students for the difficulties they would all encounter. Max had trouble keeping up with his classmates in most subject areas, and his teachers had trouble communicating with him. Lunch, recess, gym, moving through the hallways between classes — all posed significant challenges for Max. It was only through

the tenacity of his parents and his homeroom teacher that the IEP team agreed to continue his regular class placement.

What are the critical issues that an educational or rehabilitation team needs to concentrate on when helping Max? What is the best way to formulate a plan for him? Is there a role for personal assistance care or planning? These are among the issues examined by Dr. Rumrill and his colleagues in this special issue on chronic illness and health impairments.

Often persons with serious physical impairments and chronic diseases will need specialized help or professional assistance. Personal assistance services can be defined as assistance from another person with activities of daily living to compensate for a functional limitation and could include assistance with personal hygiene, medical needs, meal preparation, housekeeping and household chores, community mobility and other areas. Personal assistants allow persons with severe physical or health impairments to participate more fully in integrated settings, including education, employment, recreation and social activities, and independent living.

Because personal assistant services are frequently dependent on Medicaid or vocational rehabilitation funding, most states impose age and income limits on eligibility. Indeed, most persons who need personal assistance rely predominantly on informal systems (i.e. family, friends, neighbors, etc.) rather than on formal service providers. During childhood and adolescence, personal assistance needs of students with orthopedic and health impairments are typically filled by teachers and aides in school, and by parents and other

family members away from school. However, involving other students in personal care and assistance can be one way or orchestrating positive experiences between the student with the impairment and his or her classmates and creating a sense of comradery, especially if ways can be found to reverse the helping roles on occasion. For instance, the student with orthopedic handicaps who uses a voice synthesizer can be a 'computer tutor' to his or her classmates.

As the time approaches for the transition from school into adulthood, personal assistance needs will be of prime interest to the student and his or her family. The ITP team should identify both the anticipated personal assistance needs of the student and the resources that will be available, formal and informal, for meeting them. For many daily functions, family, friends, or volunteers can provide assistance without stigmatizing the student. For example, transportation to and from work can be provided by a family member or co-worker. In many if not most workplaces, supportive co-workers can be found who will assist the student with getting from one area to another, or even to help with feeding. However, it would be unusual to find co-workers willing to assist with toileting, to clean up after toileting accidents, to administer injections, or to take care of other personal and medical needs. It would also be stigmatizing to the student to have a family member come to his or her workplace for those purposes. In such cases, a paid assistant would be an option that needs to be explored. Though this arrangement may initially seem unusual to co-workers, customers and other members of the general population, the arrangement should eventually become accepted, particularly if the personal assistant is hired and paid by the student.

Lets now return to the case of Max. As Max entered high school, it became increasingly apparent that he was a bright young man. He took a couple of computer classes and liked the idea of a career in programming. At the beginning of his junior year, his IEP team began to address this goal by exploring post-secondary education options. Max stated during the IEP meeting that he

wanted to attend an out-of-town university. When questioned, he replied that he felt overprotected by his parents and wanted to gain more independence. He also had friends who planned to attend a state university about 2 h away and he wanted to attend the same school so that he would have friends close by. Although surprised by his request, his parents agreed to his goals.

During his junior year, Max and his parents visited the university he wanted to attend as well as two other possible schools, meeting with the faculty and the service coordinators for students with disabilities. Max's first choice seemed ideal. Although the campus was large, it had an extensive bus system that connected the residence halls, library and most of the buildings in which he would have classes. Faculty members seemed eager to meet with them and assured them that they would accommodate Max's communication methods and his needs for alternative testing procedures. The service coordinator impressed them with her knowledge of Max's physical limitations and the implications for his educational career. She also assured them that she could arrange for note takers or assistants on short notice when Max needed them for library research or other class requirements. She had also made arrangements prior to their visit for them to meet another student with cerebral palsy who had received similar services.

Now, during Max's senior year, the other members of the IEP team are helping him and his family by planning for unforeseen contingencies. The university's disability service coordinator joined the team and was instrumental in identifying potential problems they might encounter at the school, such as obtaining an accessible room in a student dormitory and locating personal assistance resources. She has also brought financial aid applications to the meetings.

One can only speculate on Max's prospects as an adult had he remained in the special school. What career goals would have been envisioned for him? Would he have made friendships with anyone who did not have a disability or was paid to help students with disabilities? What would have been the reaction of the special school IEP

team if he had indicated he wanted to go to college, live in a dormitory and learn computer programming?

Max and other persons with chronic illness discussed in this special issue of the *Journal of Vocational Rehabilitation* need to be given every opportunity to succeed in life. Personal assis-

tance, educational and rehabilitation planning, assistive devices and post-secondary education are among the ways that persons with chronic illness can meet their aspirations.

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Editor