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LIMITATIONS TO DEGREE OF INVOLVEMENT: A REPLY TO PARETTE, HOURCADE, AND BRIMER

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Parette, Hourcade, and Brimer's article on "Degree of Involvement and Young Children with Cerebral Palsy" in the Spring (1996) issue of *Physical Disabilities: Education and Related Services* is filled with questionable assumptions about children with disabilities, the nature of special education and related services, and how we should approach accountability. In their first paragraph, the authors revealed their bias that the goal of special education and related services is "ameliorating the inherent emotional, mental and or physical abnormalities associated with that disability" (p. 33). The remainder of their article is constructed to support the bias that children who can be "fixed" most easily are most worthy of services. We find this disturbing. Equally disturbing, 16 of the 22 studies they reviewed were published before PL 94-142 was implemented in 1977, with the most recent published in 1988. Education and therapy models, intervention techniques, our ability to measure progress and the outcomes that families, advocates and professionals most value have changed significantly since 1952. But all this is overlooked in their article. Finally, the choice of studies emphasizes a clinical or medical model, with therapy as an isolated service, supporting the authors' focus on remediation and options for "managed care."

There are numerous alternative perspectives. For example, interviews with 318 special educators, related service providers and parents of students with severe disabilities did not consider "ameliorating abnormalities" the only, or even primary function of therapist intervention for students with severe disabilities. They gave higher priority to developing adaptations to enhance active participation, transferring information and skills to others, and serving as a resource and/or support to the family (Giangreco, 1990). None of these functions relies on "degree of involvement" as the criterion to determine appropriateness or access to services.

Parette et al. express concerns about unchecked proliferation of related services; we share this concern. Unfortunately, their alternative to the prevalent "more-is-better" approach to decision making is an equally unacceptable "return-on-investment" model (Giangreco, 1996b). Parette et al. assert that "rationing of services would target those recipients most likely to respond favorably and significantly to the provision of services" (p.53). Norman Kunc, a self-advocate with cerebral palsy, explains how this practice of sorting people according to ability and prognosis can negatively affect people with disabilities:

The implicit message that permeated all my therapy experiences was that if I wanted to live as a valued person, wanted a quality life, to have a good job, everything could be mine. All I had to do was to overcome my disability...I wanted all those things, to have a good life, so I ended up declaring war on my body...I was part of a group with all the other abnormal, deficient, broken, disabled people. (Giangreco, 1996a, pp. 2-5)

Kunc also points out how a "return-on-investment" view presents an unacceptable challenge to basic human rights:

When you are perceived as less than fully human, what typically are rights for nondisabled people become privileges for people with disabilities...We need to establish the unconditional and inherent worthiness of people regardless of what combinations of diverse characteristics they present. (Giangreco, 1996a, pp.4-5)

As a legal issue, the courts have consistently rejected "return on-investment" as a basis for service eligibility since *Mills v Board of Education of District of Columbia* (1972) and *Pennsylvania Association for Retarded Children v Commonwealth of Pennsylvania* (1972). With passage of PL 94-142 in 1975, Congress stated a strong preference for providing education and related services for children with the most severe disabilities who, traditionally, had been excluded. More recently, the right to services for children with the most severe disabilities was reaffirmed in the case of *Timothy W. v Rochester, NH, School District* (1989). In spite of these legal decisions, criteria for determining eligibility for related services (similar to the "degree of involvement" dimensions discussed by Parette et al.) have been outlined (e.g., Carr, 1989). In response to questions about the legality of such criteria, the US Department of Education warned:

The determination to provide related services must be based on an assessment of each child's individual needs. Thus, any guidelines or policies that categorically deny related services to severely disabled students would violate the requirements of Regs.300.5 and 300.13. (see Rainforth, 1991)

If the goal is to use limited resources judiciously, a third decision-making model for IEP/IFSP teams is based on the principle of "only as special as necessary" (Giangreco, 1996b). This means that when individual outcomes are identified for a student with disabilities, the team — not individual specialists — determines what services are required for the student to achieve these outcomes by exploring combinations of natural and specialist supports that provide what students need, but not more. For example, the team for a young child with physical disabilities may determine that some needs can be addressed by school personnel available to students without disabilities (e.g., classroom teacher). Following the only-as-special-as-necessary guideline, the team may also determine that, rather than three sessions a week of both occupational therapy and physical therapy, the occupational therapist can be the primary therapist and provide integrated related service through collaboration with the classroom teacher (Rainforth, York, & Macdonald, 1992).

Giangreco (1996b) offers extensive guidance on how teams can make such decisions based on the value of "only as special as necessary," and Rainforth, York, and Macdonald (1992) suggest alternatives to traditional clinical service models for related services. Therapists' national professional organizations have long advocated such alternatives (American Occupational Therapy Association, 1989; American Physical Therapy Association, 1990; American Speech-Language-Hearing Association, 1991), in recognition that the purpose of related services is not to provide medical rehabilitation in educational settings, but to "assist a child with disabilities to benefit from special education" (Individuals with Disabilities Education Act, 1990, sec.1401[a] [17]). Studies of related services provided in the context of real activities in natural contexts, using methods from a variety of disciplines indicate that students achieve greater gains than when therapy services are provided in isolation (Karnish, Bruder, & Rainforth, 1995).

It is time to move beyond defining "degree of involvement" and deciding how to measure it. Numerous sources, including 20 volumes of *Journal of The Association for Persons with Severe Handicaps* demonstrate that persons with the most severe disabilities are capable of learning, even when their labels include cerebral palsy, mental retardation, and/or emotional and behavior problems. There are continual advances in methods to assess children with physical disabilities and document their achievements in the sensorimotor domain

(e.g., DeGangi, 1994; Miller & Roid, 1994). There is also greater understanding that sensorimotor achievement is not the greatest priority for all children with physical disabilities and their families. Although sensorimotor achievement may be intended to improve what Kunc calls "ease of living," he warns that "just because life gets easier doesn't necessarily mean that my quality of life has improved" (Giangreco, 1996a, p.7). Parents of children with disabilities have defined quality of life for their children in terms of outcomes such as health and safety, a home, personal relationships, choice and control and the ability to make contributions (Giangreco, 1996b). Achieving these outcomes may require related services, but not necessarily to "ameliorate abnormalities."

In conclusion, we agree with Parette et al. that we need to take a careful look at provision of related services in educational settings. But we believe that use of criteria such as "degree of involvement" may hinder rather than help determine appropriate support services for children with cerebral palsy and other disabilities. Such criteria discriminate against students who are labelled mentally retarded or whose cognitive abilities are difficult to ascertain due to multiple physical and sensory disabilities. "Degree of involvement" puts too much emphasis on classifying and sorting students deemed "worthy" of service and too little emphasis on determining better ways to support children with the most challenging characteristics. In doing so, we limit our own opportunities to learn more about those challenging situations, so we can advance our practices for all children with disabilities.

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