

## A Special Need

By Anke Kriske

A recent Public Agenda survey of parents of special education children provides some important insights about the experiences of this group. But it also illustrates the problems involved in trying to poll parents of such a diverse yet, in survey terms, low-incidence population.

The federal government sponsors two studies of school-aged special ed children and their parents—the Special Education Elementary Longitudinal Study and the National Longitudinal Transition Study-2—which provide vital information about the children’s experiences. But the parent survey components of those studies understandably concentrate on the children themselves and on parental involvement in school-related services, rather than exploring the parents’ own experiences and needs.

Friends and family members who provide care for loved ones often have problems of their own, which can have important health and financial consequences. As an autism advocate and mother of two special ed kids, I want to challenge the survey research community and fundraising agencies to go further in examining the needs, in particular, of special ed parents.

The Public Agenda survey did shed some light about the needs of this group, but any insights gained were only incidental to questions attempting to measure other things. For instance, in the course of probing parents’ misgivings about the special ed system, the survey found the majority (55%) believing they had to find out on their own what help was available. Seventy percent thought that special needs kids lost out because their par-

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ents were in the dark about services.

A survey with a sample size of 510, however, cannot explore the experiences of special ed parents in any detail, since they comprise only 4% of a national adult sample. (This figure is based on the one in eight public school students K-12 nationwide [13%] who has an Individual Education Program (IEP)—a written plan developed for a child with disabilities by a team of professionals and the child’s parents or guardians).

Moreover, it is difficult for any survey to assess the experiences and needs of a population as diverse as this one. Special ed students have a wide variety of conditions, ranging from visual and hearing disabilities to ADD/ADHD to mental retardation. In the autism and learning disability areas alone, special needs range from mild to very severe.

My own two sons, both of whom have had IEPs, exemplify this diversity and what it can mean. The older son has an auditory processing problem that has been remedied with mild intervention. The process of meeting his teachers and counselors for an IEP was straightforward and friendly, and he is now earning honors in high school.

The younger son has a significant learning disability in the autism spectrum. Among children with this type of disability, he is considered high functioning, but his needs place considerable resource demands on the school system. School meetings are complicated, necessitating input from a dozen education professionals. He receives speech, occupational, and sensory therapy. In elementary school, he needed a one-on-one aide, and now in middle school he is usually in a classroom with only a half-dozen kids.

The implications for parents of such wide-ranging needs are many. The Public Agenda survey, even with its small sample, found parents of severely disabled kids significantly more likely than parents of mildly disabled kids

(31% to 13%) to consider suing the school system. A 1999 NPR/Kaiser Family Foundation/Kennedy School education survey found parents of children with learning or physical disabilities significantly more likely than other K-12 parents (34% to 20%) to say they had moved a child to another school from an unsatisfactory one.

Family finances are often a problem. Difficult employment situations arise as work requirements compete with caregiving needs and parents must deal with the unavailability or prohibitive expense of after-school or vacation care for their special ed kids. Budgets are severely strained by out-of-pocket costs for the many therapies not covered by insurance, and, for many, the need to set aside extra money in trusts for life-long care for their children.

A comprehensive study of the needs of these parents is long overdue. Surveys of informal long-term caregivers provide a good model, because researchers have already developed measures of financial need, stress, and caregiver health.

But larger-sample or more targeted (even lower-incidence) surveys bear costs that are beyond the means of most support or advocacy groups. List samples are probably not the answer, since there are no adequately representative lists. Perhaps large online panels can help, since these are ideally suited for surveying low-incidence groups.

The challenge of discerning the needs of special ed children is being addressed by federal studies. But the problems of the parents of those children have so far been neglected. This situation cries out for an increase in resources and the careful work that the best survey organizations can provide. ●

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