

Book Review

Ethics of Dealing with Persons with Severe Handicaps: Toward a Research Agenda. Paul R. Dokecki and Richard M. Zaner (Eds.). Baltimore: Paul H. Brookes, 1986. xvii + 273 pages, \$21.95 (paper).

*Reviewed by Douglas P. Biklen
Syracuse University*

A special education director has a busy day ahead. Sandwiched in the middle of planning meetings, a budget meeting, time for answering a stack of mail, and filling out a state report is a 45-min meeting with a parent who has questions about her son's education. The director, who knows the parent has much to talk about, calls the parent and asks if they might meet at the end of the busy day, thus allowing them to go beyond the 45 min originally allotted. When the parent hears this, tears come to her eyes. She is overcome, she explains, because never before have school officials acted like they wanted to talk to her about her son; she always felt like she was "bothering them like a thorn in their side." In another town, half a continent away, a teenager who has Down syndrome has just arrived for work at a local sandwich shop. A film crew is on the scene to film Mary at her "integrated work site." Just before Mary is ready to walk from the kitchen to the public area of the restaurant, she pauses, looks down at her name tag on her uniform, and gives it a pat. The filmmakers know they have something. This is a scene that will bring tears to their viewers' eyes.

Why, we might ask, does the mother of the special education student cry when the special education director shows an interest in talking to her? And why will viewers of the video about Mary be moved by her sign of pride in her work? The answers to these questions are at once obvious and troubling. We are moved because good things are happening for these people. And, we are troubled because we realize that these are unusual events. If, on the other hand, it were a common, ordinary occurrence for special education directors to look forward to meeting with parents (even with parents who have tough questions), and if it were completely unremarkable or expected for teenagers and young adults with disabilities to have jobs, then we would probably not find ourselves teary-eyed in

either situation.

Now what does all of this have to do with ethics? In the very first chapter of Dokecki and Zaner's book on ethics, Elizabeth Boggs summons us as parents, professionals in human services, and interested citizens, as well as professional ethicists, to step beyond the traditional approach to ethics of "examining phenomena near their edges . . . [where] the structure of analysis can be simplified" (presumably this refers to issues such as right-to-treatment and right-to-live, or controversies over the use of aversive conditioning) and to concentrate instead on ethical concerns that arise in the everyday worlds of people with disabilities, their families, and society. She cites as examples the parameters for defining competence, the appropriate authority of parents, and debates over how much treatment people need or to which they should be subjected. We might add to this list, as Boggs seems to encourage us to do, a host of ethical issues set in the middle of daily life—not life and death matters, not even crucial controversies, but matters which, because of their fundamental and far-reaching impact on everyday life, as opposed to unique or unusual instances, deserve our riveted attention. In the example of the parent and the special education director and the young woman in the sandwich shop, for instance, we might ask, what is the status of ethics in a society where a parent cries when taken seriously, or where the public cries when they see a young person with a severe or even moderate disability take pride in herself because she has a job?

The book, *Ethics of Dealing with Persons with Severe Handicaps*, is a fascinating and challenging text. It includes chapters on ethical concerns in the middle of life, as well as ones at the edge of life. In the latter category, for example, Veatch leads us through the Philip Becker right-to-treatment/guardianship case. A central issue in this and other ethical debates is the meaning of "reasonable" and "beneficial" when applied to the vulnerable person; Zaner examines Baby Doe matters, and Turnbull and his colleagues offer an exceptionally thorough discourse on aversive conditioning. Each of these chapters brings new material to much debated questions. Interestingly, the chapters on less controversial, more

The reviewer thanks Arnold Goldstein for his helpful comments on a draft of this review.

Requests for reprints should be sent to Douglas P. Biklen, Syracuse University, 805 South Crouse Avenue, Syracuse, NY 13244-2280.

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










































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