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Book Review

Working with Women Who Have Mental Retardation: A Genetic Counselor's Guide. By Brenda Finucane. Elwyn, Inc., Elwyn, PA 19063, 1998, 81 pp., $10.00 (paperback).

When working with individuals with developmental disabilities and their families in the genetics clinic, I am often struck by the following reality: We do so well with our families with babies and young children, giving them plenty of good information on their child's diagnosis and the best preventive health care, and directing them toward community programs that may be of benefit. It seems there is a lot that we, as health care providers, can offer to families at that point in their child's life. Yet we do less well with the teens, and by the time we get to the adults, we may as well be in the twilight zone! The gaps in medical knowledge and gaps in services grow wider and wider. We say, "I don't know," a lot and use a lot of trial and error to treat common conditions. Why is it we have focused so much on the first 18 years of a person's life while relatively ignoring the remaining 40–50 years? However, better medical care and educational opportunities for babies and young children with developmental disabilities mean longer and healthier lives. So we are going to have to start thinking and learning about how to best care for people with developmental disabilities in their adult years, too, if they are going to have the quality of life we hope for them.

This was one reason that I was so excited to receive a copy of Brenda Finucane's book *Working with Women Who Have Mental Retardation: A Genetic Counselor's Guide*. This book, supported by the Jane Engelberg Memorial Fellowship of the National Society of Genetic Counselors, is a long-awaited first step in trying to identify and serve the needs of the adult population with developmental disabilities, specifically women with mental retardation. As Director of Genetic Services at Elwyn, Inc., an organization that, in addition to programs for other populations, provides educational, vocational, residential, and clinical services to individuals with disabilities, the author is in a unique position to use her genetic counseling skills in a nontraditional setting. What she has learned is invaluable to the rest of us trying to serve this same population. In her preface, Finucane remarks on her preconceived idea of what genetic counseling would involve for women with mental retardation and how those women became her teachers, showing her what genetic counseling needed to be in order to make the process most effective. This is a valuable lesson that I myself have learned over and over again from my

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patients and families: We are not necessarily the "experts," and if we would simply listen to our patients and families, they would teach us what we need to know.

The book begins with an overview of mental retardation, its history, and definition. The reader is familiarized with what mental retardation means as defined by professionals in the developmental disabilities field. This particularly important information is often lacking during genetic counselor training; however, the distinctions are relevant because of the impact that current knowledge of the causes and effects of mental retardation has on the individuals we see.

Chapter 2 is a most interesting and thought-provoking discussion of the two "cultures" of mental retardation research: the medical genetics culture and the mental retardation culture. I first became aware of this dichotomy in an article published by Hodapp and Dykens in 1994 that pointed out how research in the medical genetics field is focused on etiology with little regard for the level of functioning of an individual. In contrast, research in the mental retardation field is concerned mainly with level of IQ, with little consideration of the cause of mental retardation. Thus, geneticists will lump together in their study all individuals with the same diagnosis, such as Down syndrome, which may include wide variations in abilities. Developmentalists, however, will include all individuals with the same level of retardation in their respective study, throwing together individuals with Down syndrome, Williams syndrome, and fragile X syndrome, who each have different learning styles attributable in part to their underlying condition. The point is that each group is missing the forest for the trees! Both are losing out on valuable opportunities for collaboration in understanding the broad spectrum seen in the patients we serve.

In subsequent chapters, the myriad of issues facing parents who have mental retardation are reviewed. What is particularly interesting is the insight into the thought processes and experiences influencing the decisions of women with mental retardation to become parents. The author also discusses recurrence risk estimation for parents who have mental retardation, a topic that I feel is often overlooked during genetic counselor training. I am continually surprised by the number of genetic counseling students who are unfamiliar with the literature on mental retardation when I ask them what recurrence risk figure they would quote for a parent who has mental retardation.

Legal and ethical issues are also addressed, and as expected, more questions are often raised than answers provided. The reader is challenged to think about tough issues surrounding pregnancy and parenthood for those with mental retardation. Do people with mental retardation have the right to bear children when the community supports necessary for these parents to be successful is lagging way behind? What rights do grandparents have, who in many instances will ultimately be responsible for rearing that child? How do we achieve informed consent in a prenatal testing situation when a woman has mental retardation? Sterilization brings up additional questions. I am still frustrated by the mother of a teenage girl with mental retardation who came into my clinic insisting on a hysterectomy for her daughter because she was afraid her daughter would become pregnant. Didn't she realize there is more to this issue than simply pregnancy? What about exploitation, abuse, and sexually transmitted diseases, none of which a hysterectomy will prevent? I was also uncomfortable in this situation because I felt I was put at odds with both individuals I was trying to help. On the one hand, I am supposed to be advocating for the rights of the teenage girl to make her own decisions about her body; then I am placed in an adversarial position with the mother when I cannot agree with her wishes regarding sterilization. The growing adult population with developmental disabilities will put us in these difficult positions more and more.

All of this leads up to the final chapters, which deal with a newer approach to genetic counseling for this population, using a psychosocial model. The author elaborates on various aspects of traditional genetic counseling and how these methods are not particularly applicable to many characteristics of a population with mental retardation. How do you use risk figures and probability when your patient has difficulty understanding abstract concepts? How do you use analogies when your patient has trouble generalizing from one situation to another? These issues challenge the genetic counselor to be creative in devising different ways of communicating relevant information to women with mental retardation and their partners so they can make thoughtful decisions that reflect their needs and wishes. This discussion also made me think about the genetic counseling process for women *without* mental retardation. How many of our patients without mental retardation have difficulty with numbers and statistics and make their decisions purely on emotion and feelings? Perhaps the genetic counseling style advocated here for women with mental retardation has broader applicability to many of our patients without mental retardation as well. The author also does a good job of giving a great deal of practical genetic counseling information, much of which she has learned through trial and error, and which the practicing genetic counselor can take home and use right away.

In summary, *Working with Women Who Have Mental Retardation: A Genetic Counselor's Guide* is a valuable addition to the genetic counselor's library. It should be required reading for all genetic counseling students as part of their training program. Because it is only 81 pages, it is concise and extremely readable. The book's strength is that it is written specifically for genetic counselors, and its weakness is that it is written specifically for genetic counselors. I am afraid that its title will be taken literally, and others who might benefit from its excellent information, such as medical students, ob/gyn and family practice physicians, and nurse practitioners, might not have the opportunity to learn from it. In addition, its limited visibility, as a publication of Elwyn, Inc., may also make it less accessible to a broad audience. I would welcome more in-depth discussions and case examples of many of the issues brought forth in this book, and perhaps a more fleshed-out book would be picked up by one of the larger publishers for mass publication. This would be a great step in contributing to the limited literature on the topic of adults with developmental disabilities. I commend the author for bringing these issues to our attention and challenging us to continue thinking about ways we can best meet the needs of the populations we serve, including women with mental retardation.

REFERENCES

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Cam Brasington
Carolinas Medical Center
Department of Pediatrics, Clinical Genetics
P.O. Box 32861
Charlotte, North Carolina 28232-2861