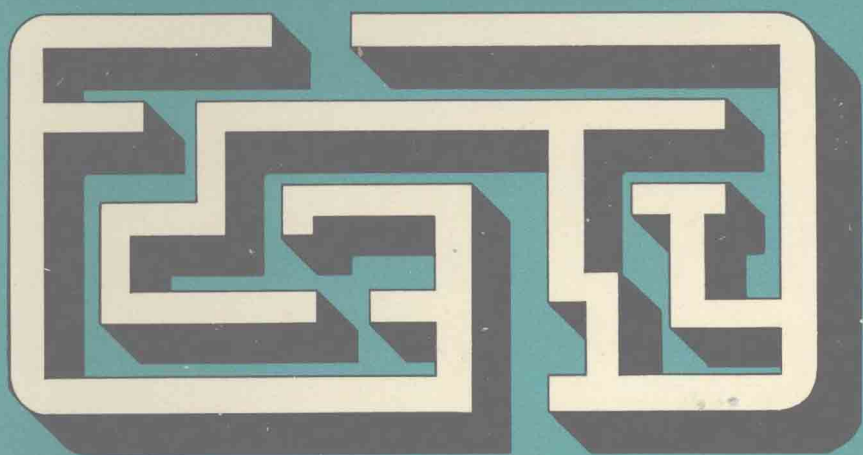


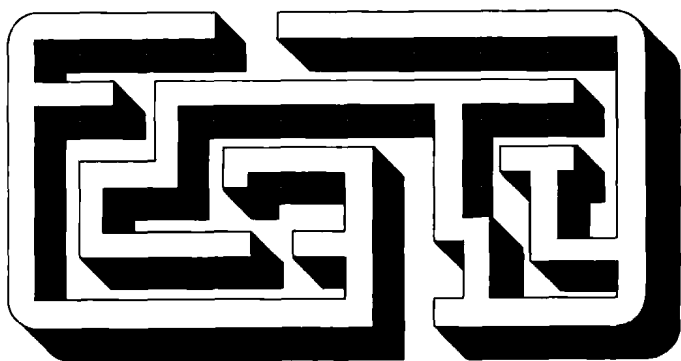
UNRAVELING THE SPECIAL EDUCATION MAZE



An Action Guide for Parents

BARBARA COYNE CUTLER

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Foreword

Articles in professional journals happily report marked success in research-oriented programs for educating special-needs children. The federal government awards millions of dollars in grants and contracts to state agencies, school systems, and educational organizations for the development and implementation of more effective educational programs. Special education receives favorable reportage in newspapers and magazines and is the subject of hopeful and heartwarming television programs. In my experience, however, few persons in the system for delivering services to special-needs children, who have the daily and long-term responsibility for the welfare of the children, are very happy.

School boards, for example, complain about the expense of special education programs and about the needs of the other children. Special education administrators describe their jobs as having too many conflicting demands, too little direct authority, and too little access to enough money for enough time to deliver comprehensive, high-quality services. Teachers describe themselves as being isolated in a large system. They assert that the demands of their jobs are not well understood and that their hard work is often not appreciated. Parents argue that there is little recognition or understanding of what they have been through, and that they have little opportunity to have an impact on the planning and administration of the services their children receive. Parents also note their dissatisfactions with services being delivered:

the poor curriculum, the lack of therapy (speech, physical), and the insufficient communication with teachers and administrators. Children, finally, express their discontent in worsening patterns of physical aggression, truancy, teasing, self-stimulation, inattention, and tantrums. The bottom line, then, is that in spite of the concern, energy, and money expended, a number of children are not getting the education which they need and to which they are entitled.

Unraveling the Special Education Maze examines this situation and offers a method for change. Three main ideas run throughout the discussion. The first is that parents do occupy an important position in the special education delivery system, but they are either largely excluded from participation, or, through passivity or fear, simply fail to effectively participate when the system is open to them. The relationship between parents and the school system is understandable in terms of the sequence of experiences undergone by many families.

The parents of a special-needs child experience sadness, bewilderment, and anxiety regarding their child's condition, his or her future, and their own sense of self-worth. Typically, parents spend many years making the rounds from one professional to another in the search for understanding of their child's condition, a prognosis, and recommendations for practical actions which they and others can take to help the child. In the process, they may spend a great deal of time, effort, and money and often obtain conflicting opinions and recommendations which do not seem to produce much beneficial change in their child. Moreover, as time goes by, the parents may feel (and may be) isolated from their own families, from neighbors, and from the community—yet the daily effort of rearing and coping with their child continues and perhaps becomes more difficult.

In the long run, the parents may become very sensitive to the opinions of others and afraid to assert themselves with professionals because they see themselves as incompetent or because they believe that by doing so they may

lose what services are being made available. Or, they may be so burned out that they wish to leave the whole job to those who are legally mandated to educate their child.

Some parents, on the other hand, become very angry or at least assertive. They may demand that certain services be delivered and may escalate the intensity of their demands when they feel frustrated. In this case, a cycle of increasing hostility between the school personnel and the parents is maintained, often to the detriment of all parties, especially the child.

The second main idea is that most of the shortcomings and problems in special education are the result of the inadequate *organization* of services rather than a lack of commitment on the part of workers in the system. The organizational sources of difficulty are numerous. For instance, the service delivery system has *multiple, conflicting goals* or functions. It is designed to simultaneously train students in basic skills, educate them in more academic skills, enculturate students so that they can become members of the larger social system, baby-sit for children while their parents work away from the home, and take custody over and control children whose behavior is difficult or impossible to manage. On the other hand, workers may expect or want the system to provide a livelihood, a sense of self-worth, and an opportunity to acquire skills enabling them to move onward and upward.

Although there is not the space here to fully address each one, other organizational sources of shortcomings in the delivery of special educational services include the following: (1) the wide range of children's needs to be served; (2) the relative isolation of special education in the school system; (3) the unclear or conflicting lines of authority among teachers, aides, special education administrators, school principals, and directors of pupil personnel; (4) the relative absence of criteria for evaluating the quality of instruction provided independent of changes in students (perhaps stemming from disagreements among theoreticians and researchers); (5) the difficulty of altering the behavior of teachers (because of

unionization, tenure, or absence of evaluation criteria); (6) the use of services provided by persons and organizations with virtually no commitment to the school system (such as cab companies, consultants, private schools, or diagnostic clinics); and (7) the often antagonistic relationship, or, more generally, the lack of a productive working relationship between the school system and the parents.

In general, long-term results of these types of organizational problems include difficulty in planning and delivering a comprehensive set and sequence of services to meet the needs of all the children; the development of behavior patterns among workers which contradict many of the goals of the organization; difficulty in evaluating both the process and outcomes of the educational program in a way that prescribes changes; difficulty in making fundamental changes in the organization itself; and increasing frustration and despair among workers, leading to half-hearted efforts and staff turnover.

The third idea that pervades the book is that parents can make important contributions to the system and can help to change it for the better—both for their own child and for the children of others. In spite of the organizational and personal problems, they can learn to understand the organization of the special education system, to evaluate services as well as their child's strengths and needs, and to develop the skills and will for communicating effectively with special education personnel.

This last idea is not wishful thinking. Both Ms. Cutler and I have found that, during the course of our training programs for families, many parents are able to transform their intimate and previously unarticulated knowledge of their children into precise descriptions and prescriptions. They learn to evaluate their children's strengths and needs and to plan comprehensive, long-term educational programs. They learn to evaluate the quality of an educational program and to make recommendations for change. And they become angry when their suggestions (often easy to institute) are not adopted (and sometimes not listened to) by school personnel who feel threatened,

harassed, or overworked. Some then become advocates for special-needs children, working very hard to produce change in the system.

The past decade seems to have shown that substantial improvement in the effectiveness of special education services will not be produced merely by the addition of money and personnel to existing systems. Perhaps what is needed is a productive relationship with parents, through which feasible and acceptable goals can be established, the knowledge of the parents can be integrated in the school and the knowledge of the teachers can be disseminated to the home, and services can be continually evaluated and revised.

This book was written primarily for parents, to help them to institute and maintain a productive relationship with special education systems, or, in the case of organizational resistance, to work to obtain the services their children need. However, the book will be equally useful to caring educators and to other professionals. It will help them to understand the position in which parents find themselves; to enlist parents as partners in developing appropriate educational programs and obtaining needed services; and to teach parents advocacy skills as part of training programs and support groups.

And no one could be better suited to portraying the points of view of all those involved in special education than Barbara Cutler. Simply stated, Barbara Cutler has been there. She is the parent of a twenty-three-year-old autistic son. Because of his unmet needs (educational, social, and therapeutic) she became involved in AMIC, an organization of parents of autistic children in Massachusetts, and has twice served as its president. Her first serious experiences with systems came about through her advocacy efforts on behalf of autistic children. From a quiet and compliant parent, she became a leading advocate, assisting key Massachusetts legislators in reviewing and revising the document which was to become the state's model special education law. She has served on the Task Force on Children Out of School, and the Massachusetts

Special Education Advisory Council, and currently serves on the Massachusetts Developmental Disabilities Council.

At the same time she was learning to become an outspoken and competent advocate, she earned her master's degree in education from Harvard University. After she trained in a special education classroom in a public school setting, she went on to direct a small model program for very handicapped adolescents. As Regional Mental Retardation Coordinator for the Massachusetts Department of Mental Health, she gained insights into the operation of still another service system.

From 1977 to the present, Ms. Cutler has been the Head Trainer on my project, Community-Based Training Programs, which is funded by the Experimental and Special Projects Branch of the National Institute of Mental Health. In her capacity as Head Trainer, Ms. Cutler has been able to employ her knowledge of the service delivery system and of parents' experiences in it, her educational skills, and her advocacy skills to the task of helping parents educate their special-needs children.

Over the years, Ms. Cutler has earned the trust and admiration of a large number of parents and professionals who have come to value her insights and experiences, and appreciate her determination to deal publicly with issues which affect the welfare of handicapped children and adults and their families.

Martin A. Kozloff

Preface

Many parents are quite literally in the dark about the rights of their handicapped children to a decent and appropriate education. Others may have heard something about the new special education law for all handicapped children, but they believe that their children are too young, too old, too handicapped, or too difficult for the public schools to educate. Yet all children, with or without handicaps, are entitled to a free public education.

Some public school systems, in their indifference to the needs and rights of handicapped children, are like mazes that bewilder parents trying to reach the goal of appropriate and beneficial services for their children. These parents find their efforts leading them to dead ends or through the same paths they have wandered in many times before. They have no way of judging how close or how far they may be from the goal. They need something to guide them.

Public Law 94-142, the Education for All Handicapped Children Act, is the map that can straighten the winding paths of the maze and lead handicapped children to the brighter future which the right educational services can bring. It provides parents with ways to avoid the dead ends and to keep moving forward.

For parents who are now frustrated by or uninformed about the educational system and its obligations to their children, this book offers the chance to learn how to use Public Law 94-142 to get to that more promising future their children deserve and to which they are entitled.

Acknowledgments

This book has been derived from a great sharing of experiences and ideas among parents and professionals over the past ten years. In the beginning, we mostly shared frustration and failure. Occasionally someone would report that through insistent and continuous contact with a school system, some parents were able to get something more for their children. The rest of us would listen carefully and try to use or adapt their techniques in the hope that our children could benefit too. In this way we inched along. It wasn't until state and national education laws were passed, guaranteeing our handicapped children the right to education, that we were able to take a giant step.

The terrain we travel is still rough, but with the resources and allies we have found, we can keep moving to reach the goal of an appropriate and adequate education for every handicapped child.

Along the way I found a number of resources, and the most important resources were people. *Parents* have been my first, special, and continuous resource. Over the years some of these parents developed into professional or paraprofessional advocates; others, of necessity, could only advocate for their own children, but they were always willing to share their needs, hopes, and experiences with others in any way that could help.

Leading the list of people to whom I am indebted are the Directors of the Parent Information Centers (PICS), Martha Ziegler (Boston), Charlotte Des Jardins (Chicago),

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Judy Raskin (New Hampshire), Bernadette Merluzzi (South Bend), Betsy Britten (Ohio), and Barbara Scheiber (Washington, D.C.). A bouquet of thanks must go to the impressive parent advocates at the Federation for Children With Special Needs: Pat Bausemer, Evelyn Doherty, Joanne Driscoll, Beverly Graham, Janice Mallett, Eileen Souza, Phyllis Sneirson, Pat Theroux, and many others in that office who sometimes sought my advice, and ended up by giving me more than I had given them.

Charlotte Aladjem, Bernice Brown, Frank Donnelly, Roz Forsyth, Cynthia Gilles, Louise Hackett, Eileen and Jerry Kramer, Regina McLaughlin, Stu Robinson, Carol Stevens, and Edith York have kept me informed, motivated, and on task as I developed an understanding of parent advocacy and its potential power.

The *legal advocates* were the first to openly stand beside parents. Without them our special education laws would be weak or nonexistent. I am personally indebted to Paul Dimond, Larry Kotin, Bob Crabtree, and Reed Martin for showing me the power of the law. Two Massachusetts legislators, David Bartley (the former Speaker of the Massachusetts House) and Mike Daly cared enough to sponsor and push the best state special education law in the nation, and to submit it to a concerned legislature and a caring governor, Francis Sargent, who signed the bill into law.

Professor Gunnar Dybwad, who has been in court speaking out for the handicapped more times than anyone can count, is the supreme and most vocal advocate for the handicapped; he has served as my model for understanding issues and for speaking up.

People inside the educational system were getting ready to join parent and legal advocates in our efforts to improve services for handicapped children. We had no trouble finding them. The foremost was Dr. Robert Audette, former Massachusetts Commissioner for Special Education. At the federal level we found Harvey Liebergott. In the cities and towns we found special education directors who cared, like Jim Underwood, Mabyn Martin, Ray Bohn, and Joyce McClelland.

In the classrooms (that is, on the front lines) I found exceptional teachers like Dr. Barbara Bruno-Golden, who first taught me that a good teacher knows how to use, work with, and support a caring parent, and Larry McIlroy, Bruce Pemberton, Diane Sullivan, and many others who have shown that they can and want to work with both students and parents.

And at the *university level*, working on understanding and changing the system, there were people like Al Murphy, Frank Garfunkel, Larry Brown, Hubie Jones, Sue Gordon, Don Maietta, and Sol Levine to provide support and advice; and since the days of my fledgling advocacy there has always been Helen Kenney, who valued the parents' contribution long before the laws were written.

Of course there are a few people who defy categorization, like Dr. Mary Jane England and Ann Connolly, who have remained strong advocates for children as they moved from service in one public agency to another; and Milt Budoff, whose determination to remain in the private sector as critic and evaluator of the educational system has allowed him to act as advocate free of the constraints that public service can impose.

Mary McKinnon, Chevy Martin, and Leela John have their own special place in the field of aggressive, and sometimes outraged and "noisy," advocacy; when I have faltered or weakened, their examples and prodding have helped me to raise my voice that one more time.

All of these people have contributed to the shaping of the ideas and experiences that form the basis of this book. Others, especially parents, who are not named because there are so many, or whose names I never knew, have shared their problems, experiences, and insights over the years. Some will recognize their stories and their contributions; others will agree with the substance; and a few may wonder how I managed to come to "that conclusion!" The applications and interpretations are my own. But I am grateful to all the people who said "Right on!" and "The book is needed. Do it!"

The "doing it" involved endless hours of turning handwritten text which was crossed-out, scribbled over, and

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One

You're Entitled . . .

Elizabeth is eight years old but can say only a few words to express her needs. She can't dress or wash herself without a great deal of help from her parents. For three years she has been in the same class, where she spends almost two hours each day working on puzzles. Her parents want her to learn more language and self-help skills.

Ms. Graham is a special class teacher who is trying to get more help for her students from the speech therapist and the occupational therapist. But they are scheduled by the special education director for only one hour each week. She is equally frustrated by the denial of her request to move her classroom to the floor where the cafeteria is so that a physically handicapped student can eat lunch with the other students. When her students' parents ask about therapy or relocation, she merely shakes her head.

Sam is eighteen but is not easily understood when he speaks. Last year he started to act out. One day he threw a book across the room and struck the teacher. The principal expelled him because the school can't deal with him. His parents can find no other programs for him, so Sam just sits at home and waits.

What do these stories have in common? They are all about children with handicaps who, in spite of requests by teachers and parents, are not receiving the educational services they need and to which they are entitled under Public Law (P.L.) 94-142.

WHAT P.L. 94-142 MEANS FOR YOUR CHILD AND YOU

By now, most of you have probably heard that P.L. 94-142 (the Federal Education for All Handicapped Children Act) guarantees a free and appropriate public education to all handicapped children. But many of you may not yet be fully aware of the important role which you, the parent, have to play in helping your child derive the maximum benefit from the law—an educational program designed and delivered to meet your child's unique needs. P.L. 94-142 gives you the right to actively participate in the process of developing an educational plan for your child. You can have a voice in determining your child's educational career by becoming your child's advocate, which means demonstrating your concern for your child and your commitment to his future by giving as much time and energy as are necessary to help him obtain those services to which he is entitled. It can be hard work, but it can make the difference between a good program and a poor one.

"Why," you want to ask, "if the law says the school systems must educate my child, do I need to become a parent advocate? Isn't the school staff responsible for finding the right program?" The answer is that of course they are responsible! However, school systems serve many children, and may overlook some of them, especially handicapped children, when priorities are being set. When the school finance committee orders the superintendent to keep costs down, who will insist that your child get the speech therapy he needs so badly? It won't be the special education director or the teacher or the speech therapist. No matter how well-intentioned, concerned, and competent they are, they still take their orders from the superintendent. If you don't advocate for the service, your child's needs may be forgotten.

P.L. 94-142 is a declaration of your child's educational rights and of your right as a parent to participate in the educational process. It is a guarantee like any other guar-