IDENTIFYING AND ADDRESSING DEVELOPMENTAL-BEHAVIORAL PROBLEMS:

A Practical Guide for Medical and Non-Medical Professionals, Trainees, Researchers and Advocates
ACKNOWLEDGEMENTS

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This book is devoted to primary care issues in the early detection, prevention, care coordination and intervention for families whose children have suspected developmental or behavioral problems (the latter also meaning mental health or social-emotional issues). We focus on the practical concerns facing physicians and nurses in private practice or public health, address their needs for brief, accurate techniques, and explain how these actually save time. We cover how to train others (or self-train) on the many issues of early identification, explain results to families, provide developmental promotion, how to find and collaborate with referral resources, and how to implement all these tasks in a way that is efficient, effective and do-able in primary care. The basics of child development and developmental disabilities are defined for nursing and medical students, residents, and other trainees.

We emphasize evidence-based methods of early detection, and hold that the process of screening and surveillance can and should rely on the same sets of tools.¹ For this reason, we often refer to the process as “screening/surveillance.” Most providers, when exposed to options among tools, choose screens that rely on information from parents.² Such tools are more efficient, are as accurate as hands-on measures, and are decidedly more useful in busy clinics. So we promulgate in this book screening/surveillance tests that parents can usually complete on their own.

Clinicians tend to think of early detection in binary terms—should this child be referred or not? But a broader view is crucial. Early detection and intervention are preventive services of three different types:

- **Primary Prevention**—meaning that we spot harbingers of problems not yet manifest, and so address “the handwriting on the wall,” by intervening with issues likely to cause problems in the future;
- **Secondary Prevention**—meaning we quickly spot mild delays, intervene, and restore children to developmental-behavioral health where possible;
- **Tertiary Prevention**—meaning we promptly treat those with manifest problems, and in so doing, prevent children’s and families’ difficulties from proliferating in even more problematic ways.

All this means that early detection is anything but binary. Rather, the measures we use must help us parse children who are:

(a) Typically developing and lacking psychosocial or biological risk factors—meaning we can reassure these families that their children are doing well and that parents are parenting well;

(b) Typically developing, lacking risk factors but whose parents need our advice and our vigilant monitoring of how well our advice worked, so that we can quickly decide when more help is needed;

(c) Typically developing or mildly delayed but with risk factors—meaning we must often marshal services other than specialized programs for children with disabilities in order to prevent future problems or further declines;

(d) Substantially delayed, with or without biological or psychosocial risk factors, and thus in need of specialized interventions.

So rather than think in simple terms, such as whether to refer/not refer to special services, instead we must think about gathering “the big picture”—using different types of evidence to more carefully decide what children and families need. The range of decisions we make requires a thoughtful recognition that early intervention is more than just special needs services. Early intervention includes:

(a) our efforts in primary care to carefully promote development and behavior;

(b) parent-training programs (when we recognize our brief advice is ineffective);

(c) community services such as Head Start, Early Head Start and quality daycare;

(d) mental health and social work services for families;

(e) specialized services provided by the Individuals with Disabilities Education Act (IDEA) for children with disabilities and private therapies.
This book also covers developmental promotion in primary care, information about the wide range of services available to our families, and how IDEA works (including terms you’ll need to know). Needless to say, we view early detection and intervention as a collaboration among medical and non-medical providers, i.e., clinicians are not alone in this process. Health care is the fundamental starting point in early detection, but working effectively with interventionists is essential for doing the best we can for children with disabilities, those with risk factors who are not yet delayed, and for helping parents do their best at promoting their children’s development.

For trainees—medical and nursing school students, pediatric and family practice residents, to those in developmental-behavioral or neurodevelopmental fellowship programs, and their preceptors—we devote space to explaining the nature of child development and its various domains. We lean heavily on the work of Lev Vygotsky to explain how children progress, i.e., via positive, joyful interactions between parent and child. To aid preceptors, we devote a chapter to training young professionals wherein the focus is on “over-training,” i.e., learning to administer measures hands-on (instead of via parent-report) in order to make the constructs of child development meaningful and real, and to aid trainees in learning to manage children and families during testing—a skill that generalizes to medical care. Included is a detailed table of milestones helpful for training. Given our evidence-based bent, we include a pre-/post-test that can be used to measure learning.

Several chapters focus on unique populations and how to work with them effectively. There is a chapter on working with families with various cultural backgrounds (e.g., Latinos, American Indians, Asians, and Middle Easterners), how these families view child development, and implications for early detection and intervention. We also cover the issues of school-age children and present an algorithm for triaging their needs. The unique challenges of premature children and those in foster care are addressed with a focus on efficient but thorough measurement and follow-up. Another chapter is devoted to psychosocial risk and what to do about it. Within, we focus heavily on language development because it is the best indicator of various types of problems and the best predictor of future success in school.

Otherwise, you won’t find much in this text on the specifics of various disabilities. There are many valuable books on these topics, described in the resource sections of relevant chapters. Our rationale for not focusing on specific conditions is that in primary care we are reasoning from the information we’ve gathered to come to a basic, non-diagnostic conclusion: a probability of a problem, its probable causes, and how to select optimal interventions. Rarely do we need to arrive at a definitive disability diagnosis, except at times, for specific health-related conditions. But even then, many health diagnoses, just like developmental-behavioral diagnoses, require help from medical subspecialists and/or non-medical professionals. This approach may feel like the antithesis of what we learned in medical training but given that “development develops and developmental problems do too” it often takes a long time, lots of information gathering, and many “eyes on the prize” to figure out the exact type of problem.

Back at the ranch that is primary care, our questions are more basic and in many ways more profound because we are “where the children are.” It is our duty to assist families with needs, but this challenging job begins by learning to recognize the likelihood of problems, however vaguely defined these may be. And so our questions are broader than just a diagnosis. Does evidence suggest we need to refer? If so, where should we refer? If not, what kind of developmental-behavioral promotion is likely to be most effective? Are there other ways to best help families do the best for their children? We must gather a range of information and synthesize it in functional ways, i.e., how best to help. If all this smacks of Hegel’s theory of dialectical materialism and Kant’s synthesis of conceptual unification and integration, well, that’s where we learned this too!

Okay, off our high horse! Meanwhile, research issues in early detection are many, and we cover these in a chapter devoted to test psychometry, optimal methods for studying existing measures, how to develop new items for research protocols, and how to translate existing measures into other languages and cultures. We also highlight directions for future research focused on the many issues in early detection and intervention in need of further study.

Other chapters concentrate on national and international models for optimal early detection and intervention, and describe initiatives in North America and world-wide. Included are projects in
developed nations such as Australia and Iceland, where there is an enormous infrastructure for promoting children’s development. But we also cover efforts in countries with numerous economic and environmental challenges, such as Haiti, where parents and providers, despite earthquakes, homelessness, cholera, and limited access to safe drinking water, are still vitally interested in children’s development and well-being. These initiatives serve as invaluable examples of approaches that could be adapted in North America—given our own extremes of wealth and poverty.

We conclude with two chapters on advocacy, including a personal perspective (from a professional whose experiences span Federal, State, and local lobbying, along with grass-roots initiatives to coordinate care and improve early detection). At the end, we summarize our thoughts and recommendations in a chapter called, “Flying Off Into Sunny Skies.”

Best viewed as a “how-to” manual, this text is sprinkled with case examples to vividly illustrate the issues at hand and how to resolve them. We used pseudonyms and stock photography when talking about children and families, except when parents prefer to speak for themselves. We’ve tried to make this book as jargon-free as possible, and so we often write in the first or second person in hopes that this book feels like a conversation with you.

Please note that this book comes with a website, www.pedtest.com/TheBook wherein we house, chapter by chapter, downloadable materials useful for training and implementation. These documents are designed to be adapted as needed. Included on the site are live links to referral services, resources for life-long learning and training, templates for referral letters, well-child visit forms that remind us of the essentials of screening/surveillance, implementation work sheets, etc. Links to specific documents housed on the website are shown in each chapter.

Finally, because all of us (and this book) are “works in progress,” please contact us through the site via www.pedtest.com/ContactUs wherein you can send us suggestions...and hopefully praise too!

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We hope you read this riveting text from start to finish, but in case you are looking for specific information, below is a guide to what’s within and how to find it. We also list the specific web pages for chapters with links to websites for professional and parenting resources and downloadable materials.

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