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Autism Services Across America

Road Maps for Improving State and National Education, Research, and Training Programs

edited by

Peter Doehring, Ph.D.
ASD Roadmap
with invited contributors

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Road Maps for Improving State and National Education, Research, and Training Programs
by Peter Doehring, Ph.D.

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About the Author

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After completing his doctoral training as a clinical and research psychologist in Canada, Peter Doehring, Ph.D., began his career developing autism spectrum disorder (ASD) screening and early intervention programs within a regional psychiatric hospital in Montreal. He then served as Statewide Director for the Delaware Autism Program (DAP), the largest specialized public school program of its kind in the United States. He led DAP through an unprecedented period of growth and change that doubled the number of students served and the number of school districts operating affiliated programs, that included the development of programs of training and oversight for ASD identification and behavior support, that revitalized a specialized postgraduate certificate for teachers of students with ASD, and that reorganized a program of residential and respite services unique within the public school system.

As Director of Regional Programs at the Center for Autism Research (CAR) at the Children’s Hospital of Philadelphia and the University of Pennsylvania, he then initiated a wide range of hospital- and community-based training programs. In this role, he served as Autism Training Director for the hospital’s Leadership Education in Neurodevelopmental and Related Disabilities (LEND) program, helped to establish a regional consortium for training, services, and research, and obtained funding from the National Institutes of Health to begin a regional research registry.

As Director of Autism Services for Foundations Behavioral Health, he led the development of a new inpatient treatment program for children and adolescents with ASD in behavioral crisis. This program was designed as a model for others to be disseminated by the parent company Universal Health Services, the largest provider of behavioral health services in the United States.

Via his consultation services—ASD Roadmap—he now provides training and strategic support to families and agencies struggling to organize, expand, and improve services and programs. Throughout his career, he has actively championed the role of research in improving practice and in 2011 edited a volume reviewing evidence-based treatments for autism. Peter is also the father of three children, including a daughter with multiple and complex developmental disabilities.

Introduction

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There has been a tremendous increase in the interest in and awareness of autism spectrum disorder (or ASD) since the 1990s. For people affected by ASD—that is, the person with ASD, caregivers responsible for that person, and for other family members—this increased interest has been accompanied by increases in the services available to them and the research conducted to identify causes, characteristics, and effective treatments for ASD. This increased interest is important, because ASD continues to have a profound and lifelong impact on the people affected by it, despite our growing understanding of ASD and of the interventions that are likely to lead to better outcomes.

A tremendous opportunity lies ahead. Service professionals now have tools and techniques at their disposal to rapidly and accurately diagnose ASD before 3 years of age and have identified interventions to address many of their most debilitating features and accompanying conditions. Those in the field are increasingly aware of the challenges faced by families and the unique needs of adults with ASD. Benefit can be had from the insights offered by people with ASD themselves. Given all that is known, why are more people affected by ASD not able to benefit from this knowledge?

Since the 1990s I have struggled with these questions through my work in different settings and with many dedicated and talented colleagues, parents, and children. Throughout my career, I have been driven by the potential of science to solve the most important questions and problems surrounding ASD and to help people living with ASD live fulfilling lives and contribute meaningfully to their communities. I have worked directly with children and their families, developed and provided training to parents and professionals, conducted research on various aspects of ASD, and provided leadership at the local and state level with the goal of influencing policy. I have worked as a leader in schools, hospitals, and universities, in the public and private sectors; and across two states, two countries, and two languages. As a parent to a young girl with multiple and complex disabilities, I have been bewildered at times by the labyrinth that is the support system in the United States and delighted when these supports can help my little girl blossom in her own unique ways.

In each of these roles and each of these contexts, the complexity of the work compelled me to examine ASD and elements from up close: As a clinician, for example, I worked to create treatment plans to meet the evolving needs of each child and parent; as a researcher, I struggled to identify how to define precisely those emerging characteristics of ASD that might help to diagnose it earlier; as a leader, I sought to coordinate programs for diagnosis and intervention so that more children could be identified and helped more quickly, with evidence-based protocols used across settings. In each of these experiences and others, I found myself dogged by the same kinds of questions: As a clinician, I wondered what kinds of training I could seek and how research could help improve the work of clinicians; as a researcher, I wondered how the research community might take its growing understanding and disseminate it through training; as a parent and professional, I wondered what kinds of policy could support these kinds of changes.

Through these experiences and others, I came to perceive similar gaps, barriers, and sources of misunderstanding and frustration across disciplines and domains. These perceptions were echoed repeatedly by others around me. Parents demanded more help and

support from professionals, and professionals blamed parents for not implementing everything the professionals recommended. Researchers wondered why clinicians could not develop or implement treatment programs that drew from their findings, and clinicians searched in vain for research that gave them useful and practical guidance. Physicians who turned to medication or other interventions to manage behavior were unable to evaluate its effects because school and community supports seem so chaotic, whereas school and community providers pinned their hopes on medication to manage behaviors that were spiraling dangerously downward. Policy makers under pressure lacked the research and data to support increasing budgets, and instead focused on increasing “efficiencies,” while everyone else was buried by paperwork that seemed to grow at the same time as the resulting services and supports were shrinking. Commiserating with other professionals and parents who perceived similar barriers assuaged my frustration enough to allow me to bury myself again in the work at hand and trust that somewhere, somehow, someone could close these gaps.

My career choices reflect my conscious attempts to bridge these gaps and overcome these barriers through increased understanding and improved coordination across elements of services, training, research, and policy; across the domains of health, education, and community services; across the public and the private sector; and between parents and professionals. In each case, I have gained a greater appreciation of the potential for services, training, research, and policy to bring about dramatic change. I have come to believe the greatest potential now lies in bridging these gaps to create a new synergy rather than reinforcing the isolated silos of expertise and the boundaries between disciplines and domains. Yet I am concerned that in the competition for decreasing resources, individual agencies and organizations will become more driven to distinguish themselves from others and not coordinate with them.

I am also concerned that a parallel decrease in the range of experience sought by professionals will compound the increasing specialization of agencies. More people are dedicating themselves to the challenge of ASD every day, and these gaps and barriers will channel their incredible passion and emerging talent into increasingly narrow fields of interest, experience, and expertise. Although professionals may shift from one agency or organization to another, most spend the majority of their career focused primarily on one element (e.g., service, training, research, policy) and working in one domain (e.g., health, education, community services) and without the opportunity to assume a leadership role in which they were expected to implement systemic changes. As a result, professionals are even less likely to accumulate the experiences needed to acquire a broad perspective.

I believe that the greater barrier to improving the lives of all people affected by ASD is no longer just a lack of knowledge: it is the fact that too many concerned about ASD do not understand all of the elements involved (e.g., services, training, research, policy). Moreover, few understand the tremendous challenge of scaling up or of building capacity—how to efficiently and effectively translate this knowledge not on a local, program-by-program basis but at the regional, state, and/or national level. This need for a more comprehensive understanding extends to parents and advocates, who view the bewildering world of services, training, research, and policy through the lens of their own particular needs. My first hope is that readers begin to grasp the potential for a more integrated network, become excited by the possibility of scientifically based services being scaled up to meet the needs of even the most traditionally underserved populations, and become emboldened to look for new collaborations beyond their own particular discipline, field of interest, and agency. My second hope is that readers discover specific programs that can serve as models for their own growth.

SECTION I: UNDERSTANDING THE SCOPE

When I originally conceptualized this book, I realized that no single volume provided a succinct summary of the scope of services needed by people with ASD across the life span; the training, research, and policy underlying these services; and the panoply of agencies and organizations involved at the local, state, and national level. As I began to accumulate examples from model state and regional programs, it became apparent that readers might find it difficult to generalize beyond these examples—however excellent and innovative—to the needs in their own programs. I also realized that effective advocacy for expansion and improved coordination will require the education of many people beyond program leaders. I initially hesitated to expand the breadth of the topics and the target audience: I considered whether it might be more beneficial to draw from others with more specific expertise in each of these areas but realized that they too would struggle to quickly outline key features within the number of pages allotted, especially if they did not fully understand and embrace the broader goals of the book. So I set out to accomplish a simpler goal: to provide parents, practitioners, and policy makers with enough knowledge to begin to advocate for and implement needed change. The first section of this book seeks to provide such a summary and to begin to identify important, cross-cutting themes.

About Autism Spectrum Disorder (Chapter 1): The challenges that ASD presents to each family vary tremendously because of their complexity (e.g., as a spectrum disorder changing with development), their lifelong impact, and their prevalence. I describe how co-occurring conditions (e.g., intellectual disability [ID], problem behavior, other psychiatric and medical conditions) might offer more immediate avenues for intervention and cross-domain coordination. The goal here is to set the stage for the more detailed discussion of the role of local, regional, and national organizations in training, research, and policy, which constitute the remainder of the book. As discussed throughout this volume, the scope of this challenge is underestimated because most professionals have experience with only a very small slice of the range of needs (e.g., they may work only with a specific age range), whereas parents of a newly diagnosed young child may be too overwhelmed to even consider what services they might need for an adult with ASD. Likewise, professionals and parents may not have grasped that one young man with an ASD may have very intensive self-care and behavioral needs such that his parents may no longer be able to care for him, whereas a college-bound young man with an ASD may need specialized coaching and support to help him to live on his own. To this end, I introduce a number of cases that I return to in subsequent chapters of the book to invigorate the discussion by reminding the reader how ASD affects individuals and families from many different backgrounds, in many different ways, and with many possible outcomes.

Services for People with Autism Spectrum Disorder: What Can This Include? (Chapter 2): Many people living with ASD grow through a broad range of services and supports in health, education, and community settings. I focus on a subset of services grouped by domain (health, education, and community support) that are commonly needed, that are offered across domains, or that play a pivotal role in helping most people with ASD gain access to other key services or settings. In this context, I touch on other important elements: which professionals typically deliver these services, whether consensus- or evidence-based guidelines for the service have been developed, and whether the service is likely to be needed by other populations. By focusing on a subset of service needs (and their associated training, research, and policy in Chapter 3), we can better characterize the complex interplay of factors.

An Overview of the Training, Research, and Policy Supporting Systems of Services for People with Autism Spectrum Disorder (Chapter 3): The effective development and expansion of services described in Chapter 2 depends entirely on the availability of associated programs of training. I broadly discuss the depth and breadth of such training programs and the potential to utilize existing avenues of training (e.g., programs leading to licensure, postgraduate training, agency-specific training), and I offer some principles and examples of a more integrated and comprehensive approach. I organize the discussion of ASD research around several critical questions (e.g., identification, prevalence, evidence-based interventions, costs, barriers) and distinguish between different kinds of research (e.g., basic, intervention, other applied research). I offer recommendations about prioritizing research to help people with ASD now, to create a culture of data-based decision making, and to bridge the gap between research and practice. I outline some general policy principles (building awareness and momentum for change; assessing and evaluating current resources; and promoting the convergence of scientific, ethical, and legal standards and oversight to drive programs of services and training) and discuss these in the context of various policy initiatives.

How It Works: The Infrastructure of Local, Regional, State, and National Agencies That Support Services, Training, Research, and Policy (Chapter 4): Any significant expansion of services, training, or research also requires that professionals understand and leverage the infrastructure of agencies and organizations. Initially, I felt this was critical for readers from other countries, whose research, health, education, and social welfare services may be funded and structured quite differently from those in the United States. But I have since learned that at least some elements of the infrastructure of services, training, research, and/or policy remain mysterious to most people here in the United States. To deconstruct this infrastructure and its constituent agencies and organizations, I describe critical dimensions such as the sector (public or private), the level (local, regional, state, or national) of the agency, and other important elements (e.g., domain, funding, mandate, mechanisms for oversight). I also illustrate the intersection of all of these elements by describing examples of agencies and programs such as those referenced elsewhere in this book.

SECTION II: EXEMPLARY REGIONAL, PROVINCIAL, AND STATEWIDE PROGRAMS

I became engrossed by the challenge of developing and overseeing large programs when I assumed leadership in 1999 of the Delaware Autism Program (see Chapter 7). After meeting with other state leaders in the National Autism Training and Technical Assistance Programs (NATTAP), I realized that others struggled with these same issues: how to provide effective training on a large scale and a small budget, how to work collaboratively with other universities and state agencies, how to bridge the research-practice gap, and so forth. I had also realized that the inner workings of other statewide programs would not be addressed via a traditional academic journal: Many of the services and training programs described here are very challenging to research effectively, and the understanding of regional models of service and training needed is more arcane than academic. It seemed like a volume with contributors offered me the best opportunity to involve colleagues whose innovative work I have admired for many years. This book began to take a clearer shape after several discussions with leaders such as Barbara Becker-Cottrill (see Chapter 5) and

with the inspiration of other volumes such as Harris and Handleman's series on programs for young children (Handleman & Harris, 2000, 2006).

The first working outline was simply a collection of detailed descriptions of model regional and state programs for services, training, research, or policy, authored by program leaders themselves, which included a brief description of their own structure and funding. These are gathered together in Section II and are summarized in Figure 1. Although it was impossible to capture the truly excellent work being done throughout the United States and elsewhere, I also realized that it would be too cumbersome to develop

The West Virginia Autism Training Center (Chapter 5)

- Based at Marshall University, projects address training/services (the Family Focus Positive Behavior Support, Autism Mentors, College Support Program for Students with Asperger Syndrome), and research/policy (Autism Registry).

Pennsylvania Statewide & Regional Autism Programs (Chapter 6)

- Led by programs in the Pennsylvania Departments of Education and Public Welfare, projects address services (Adult ASD Waivers), training (Autism Initiative Applied Behavior Analysis Supports, National Autism Conference, regional autism centers), research (Pennsylvania Autism Census and Family Needs Assessment), and policy (Autism Focus Group & Task Force, Bureau of Autism Services).

Delaware Autism Program (Chapter 7)

- Based in the Delaware public school system, projects address training (Educational Classification, Behavior Support, Teacher Certification) and services (Extended Education and Support Services).

Indiana Resource Center for Autism (Chapter 8)

- Based at Indiana University, projects address a variety of service, training, and policy initiatives.

Autism Spectrum Disorder Program at McMaster Children's Hospital (Chapter 9)

- Based at a regional hospital in Ontario (Canada), projects address services (Community-Based Intensive Behavioral Intervention Program, ASD Birth-18 Pathway Program, and School Support Program) and research.

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ASD Systems of Care for Children with ASD in Utah (Chapter 10)

- Based at the University of Utah, projects address services and related training (Early Detection in the Medical Home, Satellite ASD Services).

Kansas Instructional Support Network (Chapter 11)

- Based at the Department of Education, projects focus on training (Autism Interdisciplinary Teams, Autism Diagnostic Teams, Intense Support Teams, Structured Teaching).

Figure 1. Summary of statewide and regional programs covered in Section II.

and apply a rubric to ensure that the programs described here yielded the best outcomes. I sought to include agencies and organizations that not only have taken leadership in developing innovative programs but also have captured the variety of programs available in terms of the types of populations addressed, the domains they represented (e.g., education, health, community settings), and where they were based (e.g., in schools, hospitals, state/federal agencies, universities). With this variation, I hope that readers can identify opportunities that fit with their own unique circumstances and interests and that the specific initiatives described by the various programs highlighted in this book will themselves be replicated elsewhere.

SECTION III: EXEMPLARY NATIONAL INITIATIVES

As work on the book progressed, I learned of statewide initiatives that were inspired and shaped by the efforts of national organizations. By following closely the work of the Autism and Developmental Disabilities Monitoring (ADDM) network, I learned how a federal agency such as the Centers for Disease Control and Prevention (CDC) can mobilize a program of research to respond to emerging data (reports of high ASD prevalence in Brick Township—see Chapter 12) that, if verified, would have very significant policy implications. I also had the privilege of participating in some of the Act Early Summits initiated by the CDC, in partnership with the Association of University Centers on Disabilities. I was also excited by the work of the National Professional Development Center on Autism Spectrum Disorder (Chapter 13), whose efforts illustrate the potential depth and breadth of a well-designed training program that builds capacity by leveraging local resources. At this point, I realized that the leadership of organizations such as these could bring about a national strategy and so altered the title of the book accordingly.

SECTION IV: FACING AUTISM NATIONALLY: HOW TO IMPROVE SERVICES THROUGH TRAINING, RESEARCH, AND POLICY

What We Have Learned: How to Create Integrated Networks That Improve Access, Increase Capacity, Develop Expertise, and Address Meaningful Outcomes (Chapter 14): Repeated examples offered throughout this volume illustrate how different elements of our network (e.g., services, training, research, policy) operate independently within different domains (e.g., health, education, community supports) and often for different groups of individuals (e.g., those with and without intellectual disabilities, children versus adults). One important consequence is that the agencies and professionals have focused on narrow outcomes pertinent to their interests and have failed to capture broader and more meaningful outcomes. I suggest how a refocusing of our efforts on such outcomes at both the individual level (e.g., broad measures of well-being for children and families) and system level (e.g., ability to gain access to pivotal services), and explicit efforts to support caregivers, may help meet needs across the life span while also building bridges across domains and elements. I also touch on other aspects in each of the components of the network not addressed thus far: the division of the population according to age and presence of intellectual disability, building advocacy and awareness, and the perpetuation of domain- and element-specific silos.

I reexamine how the elements of the network (services, training, research, and policy) grow in different ways that sometimes support accelerated growth and that at other times

create barriers. For example, the lack of training resources clearly limits the rate at which overall service capacity can be scaled up and the likelihood that research and policy initiatives will improve outcomes. I conclude by offering some principles that describe how these elements (services, training, research, and policy) interact with the level of the agency and organization (e.g., local, regional, state, national) to suggest the best strategies to build an integrated network that increases overall capacity. For example, the level at which services should be provided depends on the number of people needing the services and the intensity with which the service must be delivered. Likewise, the level at which training resources are most efficiently and effectively developed depends on these factors, plus the intensity of the training required by professionals.

Where We Can Start: Immediate Opportunities for Improving the Lives of People with Autism Spectrum Disorder (Chapter 15): In the final chapter of the book, I briefly recap some of the principal themes and then outline examples of programs that integrate service, research, training, and policy and that cut across traditional domains at the local, regional, and state level to address pivotal needs for people with ASD. This includes programs better suited for regions and states with a poorly developed infrastructure (e.g., ASD identification) and others better suited for regions with more developed infrastructure (e.g., multiple levels of behavior support). I also propose other programs that offer the greatest impact relative to effort (e.g., implementation of specialized training for child care providers, paraprofessionals, and teachers). I conclude by revisiting some critical themes: the central role of caregivers, how to use evidence-based practice as fulcrum for change, and the need to build bridges with the community of those living with intellectual disability.

OTHER CROSS-CUTTING THEMES

One of the challenges of this volume was the number of themes cutting across elements and domains. At times, each of these themes appeared worthy of its own chapter or section but ultimately were subsumed into the chapters outlined in the previous sections.

Collaborating Across Agencies, Domains, and Sectors

The heterogeneity and complexity of ASD pose unique challenges to scaling up because most people with ASD will depend on interventions from a broad range of professionals and settings. As a result, a breakdown in support from any one system of care can limit the impact of all the others: An impeccably designed school-based program to address classroom-based sources of anxiety may fall short if opportunities for pharmacological management are not fully realized, and vice versa. Similarly, few agencies are well positioned to significantly address multiple elements (services versus training versus research versus policy) or address the needs of children and adults across the full spectrum of functioning. From the perspective of the child and the family, the distinctions between different elements, agencies, and even domains do not reflect a natural demarcation of needs within the child or family. These distinctions are an artifact of the functions of the institutions that have grown to address the spectrum of needs and populations. From a structural and a funding perspective, these functions and institutions have evolved to be independent and not interdependent, to be fiercely territorial and not collaborative, and to constitute separate silos and not a coordinated network. Barring significant new

investments in funding, service professionals should therefore anticipate, however, that immediate improvements will require a new level of cross-agency understanding and collaboration.

Integrating Specialized and Frontline Services

Variations in the features of ASD across individuals and the life span pose other challenges to professionals who want to help. On the one hand, professionals who do not specialize in ASD are more likely to be on the front lines and potentially can act and intervene more quickly; with the right training and support, for example, pediatricians and family practitioners can quickly screen children and identify who may need more intensive and specialized assessment. But these frontline professionals may lack the training to provide more specialized supports or lack the confidence because they are unlikely to quickly amass experience with these more specialized service needs. On the other hand, individual professionals who choose to specialize in developmental disabilities may require years of training and experience to amass the breadth of understanding needed to work more independently. The need for specialists exaggerates the silo effect noted previously, because expertise is often defined in terms of the depth and not the breadth of knowledge. As a result, individuals and organizations naturally grow in expertise by narrowing their scope, especially as funders increasingly value such expertise. The more that individuals and organizations invest in developing expertise, the less inclined they are to recognize and value the expertise of others, and there is nothing more frustrating than trying to build consensus among “experts” whose narrow-mindedness is matched only by their arrogance. In addition, funders focus on the trappings of expertise (e.g., more highly specialized programs, more grants, more publications) and not on the evidence of real, lifelong outcomes reported across the spectrum of families. Professionals must simply accept that no one agency or individual—whatever their “expertise”—can ever meet all these needs without collaborating with others, and so service professionals must always work as a team. In the last section of this volume, I discuss ways to build these strategies into the planning process.

Other Themes

- *Caregivers*: The task of coordinating care and filling in the gaps in service across these different agencies and professionals often falls on the person with the least relevant formal training—the caregiver. Caregivers live with their hopes and dreams for a better life for their child as they grow into adulthood and so can more quickly grasp a life span perspective that recognizes the person’s right to a reasonable quality of life. Given their importance, it is tragically ironic that the support and training available to caregivers is wildly inconsistent from one region to another. And yet the cost of failure in one case—that is, those resulting from the need to place a person with an ASD outside of the home—is probably equivalent to the cost of effectively supporting several people with ASD to maximize their full potential to enjoy a quality of life that the rest of us often take for granted.
- *Evidence-based practice (EBP)*: The increasing emphasis on evidence-based practice may help to reshape training and provide new opportunities for collaboration between researchers and service providers. It also reveals important gaps in service development and oversight.

- *Intellectual disability*: There are many instances in which people with intellectual disabilities may benefit from services and supports identified as effective for people with ASD, and I think this has caused people to overlook the potential synergy between programs designed for both populations, especially in rural regions.

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