Integrated Health Care for People with AUTISM SPECTRUM DISORDER

Ellen Giarelli Kathleen M. Fisher

INTEGRATED HEALTH CARE FOR PEOPLE WITH AUTISM SPECTRUM DISORDER

INTEGRATED HEALTH CARE FOR PEOPLE WITH AUTISM SPECTRUM DISORDER

Edited by

ELLEN GIARELLI, EdD, RN, CRNP

and

KATHLEEN M. FISHER, PhD, RN, CRNP

(With 27 Other Contributors)

CHARLES C THOMAS • PUBLISHER, LTD.
Springfield • Illinois • U.S.A.

Published and Distributed Throughout the World by

CHARLES C THOMAS • PUBLISHER, LTD.
2600 South First Street
Springfield, Illinois 62704

ISBN 978-0-398-09101-9 (paper)
ISBN 978-0-398-09102-6 (ebook)

Library of Congress Catalog Card Number: 201503188

With THOMAS BOOKS *careful attention is given to all details of manufacturing and design. It is the Publisher's desire to present books that are satisfactory as to their physical qualities and artistic possibilities and appropriate for their particular use.* THOMAS BOOKS *will be true to those laws of quality that assure a good name and good will.*

Printed in the United States of America
MM-R-3

Library of Congress Cataloging-in-Publication Data

Integrated health care for people with autism spectrum disorder / edited by Ellen Giarelli and Kathleen Fisher ; with 27 other contributors.
p. ; cm.
Includes bibliographical references and index.
ISBN 978-0-398-09101-9 (paper) -- ISBN 978-0-398-09102-6 (ebook)
I. Giarelli, Ellen. II. fisher, Kathleen, 1954–
[DNLM: 1. Child Development Disorders, Pervasive–therapy. 2. Delivery of Health Care, Integrated. WS 350.8.P4]

RC553.A88
616.85′882–dc23

201503188

This book is dedicated to all our families, our patients with autism spectrum disorder, their family caregivers, and the professionals who are committed to excellence in life-long care.

EDITORS

Ellen Giarelli, EdD, RN, CRNP

Ellen Giarelli is an associate professor in the Doctoral Nursing Program in the College of Nursing and Health Professions at Drexel University, Philadelphia. Dr Giarelli received a BS in nursing and a BS in biology from the State University of New York at Stony Brook, a masters degree in nursing from New York University, a Doctorate of Education from Rutgers, the State University of New Jersey, and post-doctoral education in psychosocial oncology and HIV/AIDS from the University of Pennsylvania School of Nursing. Dr. Giarelli is Co-I of the CDC funded Study of Epidemiology of Early Development (SEED) and was PI of an initiative funded by the Philadelphia Health Care Trust to integrate nursing into the care of people with ASD. She was research project director of the UPENN School of Nursing CDC funded Center for Autism and Developmental Disabilities Research and Epidemiology (CADDRE) and the director of the Pennsylvania Autism and Developmental Disabilities Surveillance Program (PADDSP). In addition to the awards from the CDC, her funded projects include an R21 from NIH/NINR to study self-management of genetic disorders. She is a Certified Registered Nurse Practitioner in Pennsylvania and principal investigator for several externally funded studies of autism spectrum disorders.

Kathleen M. Fisher, PhD, RN, CRNP

Kathleen Fisher is Professor of Nursing at Drexel University. She is a family nurse practitioner with a PhD in public administration and Health Policy from Penn State University. In 2001 with the collaboration of state and county agencies, she developed the South Central PA Health Care Quality Unit (HCQU), to oversee care and services for individuals with intellectual and developmental disability (I/DD) in nine counties in Pennsylvania. Dr Fisher has conducted a NINR funded study to describe decision making by proxy for those with I/DD also in Pennsylvania. Her research interests include intellectual disabilities (ID), proxy decision making, and exploring transitions with aging for those with ID.

CONTRIBUTORS

Joan Rosen Bloch, PhD, CRNP

Joan Rosen Bloch joined Drexel University as a full-time faculty member in 2005. She received her BSN from Thomas Jefferson University in 1978, MSN from the University of Pennsylvania in 1981, and PhD from the University of Pennsylvania in 2001. During her doctoral studies, she was awarded a two-year NIH pre-doctoral research fellowship in the Center for Vulnerable Women, Children and Families. Upon completion of her PhD, she was awarded a NIH post-doctoral research fellowship at the Center for Health Outcomes and Policy. Complementing her doctoral coursework at the University of Pennsylvania's School of Nursing was extensive coursework in both the School of Medicine and the Wharton Business School, enhancing her perinatal epidemiology and maternal-infant policy research abilities. As a certified Women's Health Nurse Practitioner since 1981, she has practiced in a variety of settings: City clinics, HMOs, and private practice. Her current practice in a Philadelphia federally-funded prenatal center informs her teaching and research. At Drexel University, she teaches women's health and research to BSN, MSN, and doctoral nursing students. She has received funding to investigate caregiver issues related to parenting children with neurodevelopmental disabilities throughout the life cycle.

Michael J. Brenner, BS, MPH

Michael Brenner graduated from the University of Vermont with a degree in microbiology and completed public health training at the University of Pennsylvania's Master of Public Health program. During his undergraduate career, Michael worked for a social services agency providing crisis intervention and residential services to the developmentally disabled in Vermont. After working in a specialized inpatient psychiatric unit for children with disabilities in Maine, he decided to pursue graduate training in public health in order to better understand the epidemiology of complex conditions like ASDs. Michael is currently a medical student and continues his research in the field of epidemiology.

James E. Connell, PhD

James Connell is a practicing psychologist, a nationally certified school psychologist, and a board certified behavior analyst conducting mental health, behavioral health, and educational research in community settings. Dr. Connell is an associate professor at Drexel University in the School of Education. Prior to Drexel, he was a research assistant professor in the Department of Psychiatry at the University of Pennsylvania and an assistant professor in the School Psychology Program at Temple University. For the past 10 years, his scholarship and clinical practice has focused on the conceptualization and implementation of evidence-based interventions in community settings, and the development and refinement of consultant-driven procedures to ensure program fidelity. He has more than 15 years of experience working in school systems and mental and behavioral health settings providing consultative support to direct care staff and educators on the implementation of evidence-based interventions. He has published numerous studies identifying external variables associated with the adult behavior change needed to ensure successful program implementation and has critiqued and edited numerous peer-reviewed papers on the same topic. He has taught graduate level courses in academic and behavioral interventions, and school and community-based consultation models and procedures.

Meghan N. Davignon, MD

Meghan Davignon received her MD from the University of Colorado Health Sciences Center and her pediatrics residency training through The Children's Hospital Colorado. She completed a fellowship in Developmental and Behavioral Pediatrics in 2014 at The Children's Hospital of Philadelphia and currently works as a developmental pediatrician at Kaiser Roseville Medical Center in Northern California. She specializes in the diagnosis and care of children with autism spectrum disorders and other neurodevelopment disabilities. Her research interests include improving the hospital experience for patients with ASD and determining predictors for successful outcomes for children with autism spectrum disorders who have been referred for behavioral therapy.

Leah I. Stein Duker, PhD, MA, OTR/L

Leah I. Stein Duker is a research assistant professor in the Mrs. T.H. Chan Division of Occupational Science and Occupational Therapy at the University of Southern California (USC). She earned her bachelor's degree in neuroscience and behavioral biology from Emory University, her master's degree in occupational therapy from USC, and her PhD in occupational science from USC. She has over 10 years of experience working with individuals with autism spectrum disorders and other developmental and physical disabilities, and her practice has focused on pediatrics in both the school and clinic settings. Her research interests include the impact of the physical, sensory, and social environment on patient and family experience during distressing health care procedures. Specifically, she is interested in the efficacy of environmental modifications to reduce physiological stress and anxiety, behavioral distress, and perception of pain in a variety of patient populations. She also has experience in the collection, analysis, and interpretation of both traditional wired and innovative wireless electrodermal activity data in the measurement of sympathetic stress and arousal. She has presented extensively, both locally and nationally, and has over ten publications in these areas of research.

Jennifer Harrison Elder, PhD, FAAN

Jennifer Harrison Elder is a professor and the associate dean for research at the University of Florida's College of Nursing. Prior to that, she served as Chair of the Department of Healthcare Environments and Systems. She has taught across all levels of the curriculum since her initial appointment in 1992 and currently focuses on directing the PhD program, teaching research methods courses for PhD students and providing research experiences for undergraduate honors students. Dr. Elder has spent 32 years studying autism and related child neuropsychiatric disorders, methods of educating families, and reducing caregiver stress of children with autism. Dr. Elder has been the primary investigator on four NIH/NINR grants and co-investigator on three others. She has given numerous international research presentations including an invited presentation in New Delhi by India's president. She is a fellow in the American Academy of Nursing and frequently reviews for NIH, and the American Nurses Foundation.

Marie Foley, PhD, RN

Marie Foley is the dean of the College of Nursing at Seton Hall University in South Orange, New Jersey. Dr. Foley has been a nurse educator since 1985. Her teaching experience includes most levels of nursing education, and programs. She has taught in BSN, RN to BSN, CNL, MSN and PhD programs at Seton Hall University, Kean University, the College of Saint Elizabeth, and NYU. She is a pediatric and school nurse and has taught courses in growth and development, pediatrics, research, and nursing theory. Her research interests include topics in school nursing, child temperament, ADHD, and parenting, mentoring school nurses and new faculty. She is a Certified Clinical Nurse Leader, and NJ-Certified School Nurse. She is a member of the National Association of School Nurses and the School Nurse Educator special interest group Sigma Theta Tau International, Eastern Nursing Research Society, and the Natioinal League for Nursing. She received her BSN from Fairleigh Dickinson University, her school nurse certification from Seton Hall University, her MA in nursing education and a PhD from New York University

Maria A. Fragala-Pinkham, PT, DPT, MS

Maria A. Fragala-Pinkham is a physical therapist and clinical researcher in the Research Center for Children with Special Health Care Needs at Franciscan Hospital for Children (FHC), Boston, MA. Dr. Fragala-Pinkham received her bachelor of science degree in physical therapy from Northeastern University, Boston, MA; a master of science degree in human movement science from the University of North Carolina–Chapel Hill; and a doctor of physical therapy degree from Massachusetts General Hospital Institute of Health Professions in Boston, MA. In her current position, Dr. Fragala-Pinkham conducts clinical research, provides PT intervention for outpatients, and directs the Adaptive Sports Program at the hospital. She has 30 years of clinical experience and has worked in a variety of clinical pediatric settings including early intervention, schools, home care, and hospital inpatient and outpatient programs. In addition, she has developed community-based adapted sports and fitness programs for children including an adapted ice skating program and an adaptive bicycle program. She is one of the senior authors of the Pediatric Evaluation of Disability-Computerized Adaptive Test, a pediatric functional outcome measure that was released in 2012. Dr. Fragala-Pinkham has published articles on the topics of pediatric outcome measures, effectiveness of therapeutic interventions and fitness for children with disabilities. She has presented on clinical topics and research findings for local, national, and international audiences.

Kathleen G. Freeman, PhD, RNC-NIC

Kathleen Freeman is adjunct faculty at the Drexel University, College of Nursing and Health Professions. She has been in nursing education for over 20 years and has taught at the University of Pennsylvania, Rutgers University, and the College of New Jersey. Within undergraduate, graduate, and RN-BSN education curriculums, she has taught human development, maternal-child health, community health, nursing foundations and theories, and autism. Certified in neonatal intensive care nursing and holding a Certificate in Applied Behavior Analysis from Rowan University, Dr. Freeman has a clinical background in the developmentally vulnerable and has expanded this expertise to include autism spectrum disorders (ASD) as a parent of an adult child with ASD. She contributed one of the first articles published on compliance with health procedures for the child with ASD in *Pediatric Nursing,* Dr. Freeman's passion for maternal-child health and improving the lives of those affected by ASD leads her to research and projects that include enhancing nursing ASD education, perinatal risks for ASD, developmental issues for the family with a child with a disability, family advocacy for services, and behavioral pediatrics. She received her BSN from the University of Pennsylvania, MS in maternal-child health nursing from the University of Delaware, and a PhD from the University of Maryland.

Eron Y. Friedlaender, MD, MPH

Eron Friedlaender is an associate professor of clinical pediatrics at the University of Pennsylvania School of Medicine and an attending physician in the emergency department at The Children's Hospital of Philadelphia. Dr. Friedlaender completed formal training in child advocacy and injury prevention through an NIH training grant, during which time she earned a masters in public health. She has investigated patterns of healthcare utilization by victims of child maltreatment, studied risk factors for injuries within the built environment, and served as principal investigator of the Injury Free Coalition for Kids in Philadelphia. She currently leads development of care initiatives and programming within the hospital to ensure access to and delivery of quality services to children with autism spectrum disorders.

Terisa P. Gabrielsen, PhD

Terisa Gabrielsen is a school psychologist specializing in interdisciplinary collaboration to improve care and treatment options for children with autism spectrum disorder. Following her doctoral training at the University of Utah and internships in Utah schools and The Children's Hospital of Philadelphia, she was a post-doctoral fellow at the Center for Autism Research in Philadelphia. She is now training school psychology students at Brigham Young University and continues her community outreach and interdisciplinary research on early intervention for toddlers and social skills training for teenagers.

Marcia R. Gardner, PhD, RN, CRNP, CPN

Marcia Gardner joined the faculty of the College of Nursing at Seton Hall University, South Orange, New Jersey, as an associate professor. She received a BSN from

Georgetown University, a master's in nursing from New York University, a post-master's certificate as a pediatric nurse practitioner from the State University of New York at Stony Brook, and a PhD in nursing science from the University of Pennsylvania. She was a clinical fellow in the Leadership in Neurodevelopmental Disabilities program at Children's Hospital of Philadelphia and a fellow in the AACN Academic Leadership Program. With an extensive background in high-risk neonatal care as well as in general pediatrics, she has taught pediatric nursing at both the undergraduate and graduate levels. She has been a department chair and assistant dean for both BSN and MSN programs. She is certified in pediatric nursing and as a pediatric nurse practitioner by the National Certification Board of Pediatric Nurse Practitioners and Nurses, and has research interests related to parenting of developmentally vulnerable infants and children.

Connor M. Kerns, PhD

Connor Kerns is trained in clinical psychology and Assistant Research Professor in the AJ Drexel Autism Institute and the Department of Psychology at Drexel University in Philadelphia, PA. Her clinical work and research focuses on the overlap, assessment, and treatment of emotional and stress-related disorders in individuals with ASD.

Paul A. Kettl, MD, MHA

Paul Kettl is currently Clinical Professor of Psychiatry at the Perelman School of Medicine of the University of Pennsylvania, and education director for behavioral health at the Philadelphia VA. Formerly, he served as chair of the Department of Psychiatry at Penn State's College of Medicine. He enjoys teaching, and last year, received the Dean's Award for Excellence in Clinical Teaching at an Affiliated Hospital, Perelman School of Medicine of the University of Pennsylvania, and received the Distinguished Educator Award from Penn State's College of Medicine along with other teaching awards from thirteen separate medical school classes from Penn State. He has served as a consultant in the past for seven pharmaceutical companies and has been named by his peers as one of the "Best Doctors in America" every year since 2003. He has a longstanding interest in public policy, and was the Democratic nominee for US Congress from his district in the past, losing to the republican incumbent in the general election.

David S. Mandell, DSc

David S. Mandell is an associate professor of psychiatry and pediatrics at the University of Pennsylvania's Perelman School of Medicine, where he directs the Center for Mental Health Policy and Services Research. He is the associate director of the Center for Autism Research at The Children's Hospital of Philadelphia. His research focuses on improving the quality of care individuals with autism receive in their communities and studying the best strategies to successfully implement proven-efficacious practices in community settings. Dr. Mandell is the author of more than 80 peer-reviewed scientific publications, many of which examine correlates of unmet need among children with psychiatric and developmental disabilities and strategies for reducing disparities. He co-chaired the Commonwealth of Pennsylvania's Autism Task Force from 2003 to 2006 and consults with the Department of Public Welfare to help them develop appropriate policies to meet the needs of families of children with autism. He currently serves as a member of the US Department of Health and Human Services Interagency Autism Coordinating Committee. Dr. Mandell holds a bachelor of arts in psychology from Columbia University and a doctorate of science from the Johns Hopkins Bloomberg School of Public Health.

Judith Miller, PhD

Judith Miller is assistant professor of psychology at the Perelman School of Medicine, University of Pennsylvania. She is a clinical psychologist with over 20 years of research and clinical experience with individuals with ASD, of all ages and levels of functioning. She directs the Research Assessment Clinic at the Center for Autism Research, the Children's Hospital of Philadelphia, and an ASD training program for psychology fellows, interns, and graduate students. Her research interests focus on identifying the essence of ASD to improve screening, diagnosis, and diagnosis of co-occurring conditions. She and her colleagues have worked closely with several units at The Children's Hospital of Philadelphia to improve the hospital experience for patients with ASD and their families.

Surabhi Mulchandani, MS

Surabhi Mulchandani is the manager of genomics education and outreach at the Division of Genomic Diagnostics at the Children's Hospital of Philadelphia (CHOP). Ms. Mulchandani is a board certified and licensed genetic counselor. She received a masters degree in molecular and human genetics from India and a masters degree in genetic counseling from California State University, Northridge. Ms. Mulchandani worked as a senior genetic counselor in the genetic testing lab at CHOP for five years before moving on to her current role. As a genetic counselor, Ms. Mulchandani interpreted complex data generated by genome wide array technology in context of patient's clinical information, provided genetic education, counseling, and risk assessment and served as a bridge between clinicians and the lab. In her current role, Ms Mulchandani manages various educational activities for the division including the fellowship program for future lab directors, and genetic testing rotations for genetic counseling student in addition to leading a project on genetic testing utilization for The Children's Hospital of Philadelphia. She has been involved in multiple research studies on genomic testing. Ms Mulchandani's interest lies in understanding the clinical, psychosocial, ethicolegal, and economical impact of genetic testing on patients, families, health care providers, and the society as whole.

Craig Newschaffer, PhD

Craig Newschaffer is founding director of the A.J. Drexel Autism Institute at Drexel University and a professor in the Department of Epidemiology and Biostatistics at the Drexel University School of Public Health. Dr. Newschaffer is an epidemiologist whose main research focus is the discovery of modifiable autism risk factors. He is principal investigator of an NIH Autism Centers of Excellence (ACE) research network that implements the Early Autism Risk Longitudinal Investigation (EARLI)–a large cohort study designed specifically to study pre, peri- and neonatal autism risk factors and biomarkers by following mothers of children with autism at the start of subsequent pregnancies. Dr. Newschaffer has also been a site PI for the ADDM Network and SEED Studies, and currently leads a project exploring innovative approaches to autism case confirmation for the National Children's Study (NCS). He is a fellow of the American College of Epidemiology and serves as an associate editor of the *American Journal of Epidemiology* and on the editorial boards of *Autism Research* and the *Journal of Neurodevelopmental Disorders.*

Romy Nocera, PhD

Romy Nocera is a research assistant professor and the director of clinical research in the Department of Emergency Medicine. She received her BS from the University of Pittsburgh, her MA and PhD from Bowling Green State University, and completed neuroscience fellowships at BGSU and Lankenau Institute for Medical Research. She has taught numerous courses in psychology, psychobiology, gerontology, and research methods and statistics, and was awarded the I.M. Freeburne Award for Excellence in Teaching at BGSU. She currently teaches in the annual Translational Medicine Research Course for fourth-year medical students and serves as a preceptor for their simulated research projects. In addition, Dr. Nocera heads the EM Resident Research Program, and serves as advisor to several pre-medical master's students in fulfilling their research requirements. She oversees multiple funded clinical trials and maintains her own program of research in the field of neuroscience. Her past research interests and experience included neuropsychological assessment of persons with Alzheimer's disease, caregiver stress, neuronal receptor expression in Alzheimer's and in normal aging, and stem cell treatment for ischemic stroke. She is currently conducting research focused on relationships between weather variables and stroke incidence, and in the relationship between aphasia at stroke onset and patient outcomes. She is a member of the Society for Neuroscience.

Margaret E. O'Neil PT, PhD, MPH

Margaret O'Neil is associate professor and research faculty member in the Department of Physical Therapy and Rehabilitation Sciences at Drexel University, Philadelphia, PA. She has a secondary appointment in Drexel's School of Public Health, Department of Community Health and Prevention. She received her bachelor of science degree in biology from Providence College, Providence, RI; her a master of science degree in physical therapy from Duke University, Durham, NC; her master of public health degree from the University of North Carolina– Chapel Hill and her PhD from Drexel University (formerly MCP Hahnemann University). Dr. O'Neil's research focuses on measuring physical activity and fitness in children and youth with physical disabilities (cerebral palsy) and chronic conditions (obesity). In addition she examines the effect of innovative interventions (i.e., active video gaming) to promote physical activity and fitness, and conducts both laboratory-based and community-based research studies to examine reliability and validity of physical activity measures and to examine the effect of activity-based interventions on physical activity and fitness in children. She has been the recipient of multiple grants including NIH and the Department of Education. Dr. O'Neil has published articles on the physical activity and fitness measures and outcomes for children with disabilities and obesity and she has done multiple local, national, and international presentations on these topics.

Elizabeth Pfeiffer, PhD, OTR/L, BCP

Beth Pfeiffer is an associate professor at Temple University where her primary responsibilities are teaching and research. Her research focuses on sensory processing, autism, and mental health across the lifespan. Dr. Pfeiffer has completed effectiveness studies on the use of sensory-based interventions in both children and adults. Her recent work focuses on developing a measure to assess the impact of the sensory environment on participation in daily activity for very young children with autism spectrum disorders. Additionally, she was recently funded to develop advocacy-based ecological interventions, and study the impact of the sensory environment on employment outcomes for adults with autism spectrum disorders.

Jennifer A. Pinto-Martin, PhD, MPH

Jennifer Pinto-Martin is the Viola MacInnes/Independence Professor and Chair of Biobehavioral Health Sciences in the University of Pennsylvania School of Nursing with a secondary appointment in the Department of Epidemiology in the School of Medicine. She is the director of the University of Pennsylvania's Masters of Public Health Program. Dr. Pinto-Martin began her career as an epidemiologist and as the project director for the Neonatal Brain Hemorrhage (NBH) Study, a longitudinal study of neonatal brain injury in low birthweight infants. The NBH Study has had continuous NIH support for this research since 1984 and has conducted five separate assessments of the cohort. Dr. Pinto-Martin's primary research focus is the epidemiology of autism spectrum disorder. She is currently the director and principal investigator of the Pennsylvania Center for Autism and Developmental Disabilities Research and Epidemiology (PA-CADDRE), one of six such centers funded by the Centers for Disease Control and Prevention to study the etiology of ASD. PA-CADDRE is currently involved in data collection for the Study to Explore Early Development (SEED), a multi-site, case-control study of the risk factors associated with ASD. In addition, Dr. Pinto-Martin just completed a study funded by NIH to assess the prevalence of ASD in the NBH cohort. Dr. Pinto-Martin is also working with the International Clinical Epidemiology Network on a study, funded by NIH- Fogarty, on the prevalence of ASD and other childhood disabilities.

Marian Reiff, PhD

Marian Reiff has a PhD from Columbia University in sociomedical sciences, specializing in medical anthropology and public health. She also has a master's degree in social work and social policy from the London School of Economics. She has taught medical anthropology, and has clinical experience as a social worker in medical, psychiatric and community settings. Dr. Reiff is a senior research investigator in the Division of Translational Medicine and Human Genetics at the Perelman School of Medicine, at the University of Pennsylvania. She was principal investigator on a research project funded by the National Institutes of Health that used mixed methods (including in-depth interviews and surveys) to examine the impact of uncertainty about the results of genomic testing on children with autism and their families. Dr. Reiff's research explores the psychosocial and cultural contexts of health behavior and health care. In addition to investigating the implications of genome-wide testing for families and healthcare providers she studies public attitudes regarding genetics and mental illness.

Lindsay Shea, DrPH

Lindsay Shea is the director of the Eastern Region Autism Services, Education, Resources and Training Collaborative (ASERT) Eastern Region at Drexel University and senior manager of the recently launched A.J. Drexel Autism Institute. Dr. Shea has led and managed autism-focused policy and research projects locally, in Pennsylvania and with a national scope for 10 years. Dr. Shea first-authored the Pennsylvania Autism Census Report and her research interests are based in creating and utilizing an evidence base in forming, evaluating, implementing, and modifying social and health policies.

Margaret C. Souders, PhD, CRNP, PNP

Margaret C. Souders is an assistant professor at the University of Pennsylvania, School of Nursing and a clinician educator. She has an appointment in the Clinical Genetics Department at The Children's Hospital of Philadelphia as a pediatric nurse practitioner. She has completed a two-year post-doctoral fellowship in the Center for Sleep and Respiratory Neurobiology at the University of Pennsylvania where she has a research program in sleep science. After conducting over 400 home visits and talking with individuals with autism spectrum disorder (ASD) and their caregivers, we identified that the environmental modifications, behavioral strategies and intensity of the sleep intervention needs to be tailored to the specific characteristics of the individual with ASD, the detailed needs of the family, and the complexity of the sleep problems. She is a member of a multi-disciplinary team of experts including a nurse practitioner and sleep scholar from the University of Pennsylvania, a behavioral psychologist and autism expert from Drexel University, an occupational therapist and sensory expert from Jefferson University and caregiver of a child with ASD and insomnia from Philadephia.

Renee Turchi, MD MPH, FAAP

Renee Turchi is the medical director of the PA Medical Home Program which is a statewide and state/federally funded medical home program for pediatric practices in the Commonwealth of Pennsylvania. As medical director of the Center for Children with Special Health Care Needs at St. Christopher's Hospital for Children, she delivers primary care for children and youth with special health care needs and has multiple grants supporting evaluation of health care delivery to this fragile population of children. She is an associate professor at Drexel University School of Public Health and College of Medicine.

Carl V. Tyler, Jr., MD, MS

Carl V. Tyler is the Geriatrics and Research Director for the Fairview Hospital/Cleveland Clinic Family Medicine Residency Program and associate professor in Cleveland Clinic Lerner College of Medicine of Case Western Reserve University. After graduating from Northeastern Ohio Universities College of Medicine (now Northeast Ohio Medical University), he completed one year of post-graduate studies in psychiatry and human behavior at the University of California, Irvine, followed by a three-year residency in family practice at Fairview General Hospital. He is board-certified in family medicine and geriatric medicine. He completed two post-doctoral fellowships through Case Western Reserve University: the first, concentrating in aging and disability, leading to a master of science degree; the second, an NIH-sponsored fellowship in practice-based research design and methodology. Dr. Tyler joined the faculty at Fairview in 1995. He serves as director of the Developmental Disabilities-Practice Based Research Network, a multi-stakeholder research group with representatives from the advocacy, service, and health care communities. Dr. Tyler's clinical and research interests include the primary medical care of adults with developmental disabilities and practice-based health services research utilizing electronic health records. Dr. Tyler and his wife, Maca, have three daughters, Ana, Aleksandra, and Natalija.

Kate E. Wallis, MD

Kate E. Wallis is currently a resident physician in the Department of Pediatrics at New York University School of Medicine. Dr. Wallis received her MD and MPH degrees from Stony Brook University School of Medicine. She earned her BA from the University of Pennsylvania. She has been working with individuals with autism spectrum disorder for 15 years. Dr. Wallis's major research interests include the epidemiology of autism, the history of medicine, and improving care for individuals with chronic medical problems. She has published in the field of developmental disabilities, writing about the difficulties of screening for autism spectrum disorder across different cultures and the diagnosis and management of enuresis and encopresis in typically and atypically developing children. Dr. Wallis will be starting a fellowship in behavioral and developmental pediatrics at The Children's Hospital of Philadelphia.

FOREWORD

Every one of us depends on health care providers for essential preventative, treatment, and emergency care for ourselves or our loved ones. This continuum of care ideally includes personalized, evidence-based support for prevention and wellness, maintenance, and in illness and crisis. For routine care, we trust our healthcare providers to check up on us and tell us if things are going well or if something about our health has gone awry. We make calls, wait for our appointments, fill out checklists, answer questions, and participate in exams. These encounters might be routine or life-changing. Having that care is something we often take for granted when we go to the doctor's office. Most of us can count on being able to report our history and symptoms and trust the people we encounter are there to help us.

Now, what if you were one of the 1–2% of people who has autism spectrum disorder (ASD)? How would that change your healthcare encounter? From early on, your parents may have a nagging feeling that something is different. They may question if you can hear and wonder why you do not turn around when they call your name in that sweet baby voice they use to get your attention. At the 18-month well-baby check-up, your mother might keep a close eye on the nurse and doctor for any sign that something is different or wrong. She might apologize when you cry and arch your back as you are examined. She might be anxious and relieved at the same time when asked to answer questions about how many words you are using, if you smile when others smile at you, if you point out objects, if you pretend to talk on the phone. You may be frustrated that you cannot say you are hungry, bothered when people interrupt your close inspection of a toy to get you to look at them, and distracted by the hums and whirls of the machines and sounds in the background.

From the earliest age, when the social communication and interaction and behavior signs of autism emerge, life is different for people with ASD. These differences are biologically-based and result in lifelong differences in processing information and experiencing the world. In addition to these core aspects of ASD, people with ASD are likely to have co-occurring challenges in areas such as sleeping, eating, sensory processing, attention, and anxiety, among others. People with ASD may find the unpredictability of office visits to be disconcerting. The unfamiliar people with unclear intentions in the midst of strange sights, smells, and sounds may be overwhelming. Some people with ASD may react with outbursts that are frightening to those not familiar with the person, or they may just shut down and not respond. A person with ASD may not be able to tell you where it hurts, or that they even have pain in the first place. Even before the appointment it may take extra steps and preparation to get ready for an office visit. Then, supports throughout the visit may be necessary. In these busy times, many healthcare professionals may not be interested in taking the time necessary to address the special needs that someone with ASD may have. Getting routine health care can be a challenge for many reasons, but the main barrier comes from the breakdown in efficient communication between provider and patient when they are not able to understand each other. This book provides the tools and information so the healthcare professional can think differently about caring for this patient, and see through his or her eyes.

Given the current prevalence estimates and improvements in awareness of ASD, it is very likely that most healthcare offices will have patients on the spectrum at some time or another. Ideally, each person has access to a Medical Home that provides accessible and family-centered care across the lifespan. People with ASD may have unique developmental challenges, but they face a range of health issues like all people. Many of these may be compounded by an ASD. Access to quality care is a challenge and many individuals have no one to transition to when aging out of pediatric care. We know very little about the long-term health effects of activity limitations, restricted diets, or other compounding behavioral challenges. For too many, basic healthcare needs have been overshadowed by ASD with potentially treatable health issues explained away as just another part of the ASD. There is a great need to change that bias so that each person has access and is involved in what is needed to help them live healthy lives.

This volume edited by Dr. Ellen Giarelli and Dr. Kathleen Fisher is a much-needed resource with important information from the 2014 conference "Creating Integrated Healthcare Services for people with Autism Spectrum Disorder" sponsored by Drexel University College of Nursing and Health Professions and the AJ Drexel Autism Institute. The information and tools are essential to improve the care and support of people with ASD. Compilation of the information shared during the conference can help move health care forward by recognizing that people with ASD face the range of issues that all individuals may encounter in addition to more complicated and unique challenges requiring specialized strategies and attention. The presentations summarized here and the additional chapters share the importance of early, continuous, coordinated, and individualized care that is integrated into the existing health care system. Examples of models and policies that have improved the access, experience, and outcomes for patients with ASD are shared. In addition, the importance of continuous quality improvement through data collection and monitoring of outcomes is emphasized. This information is essential for addressing the capacity crisis we have in providing routine, specialized, and emergency care for individuals with ASD.

This volume brings together a wealth of expertise with information and strategies across the lifespan. As a result of these efforts, I hope that more people with ASD will feel they are part of a trusted health care team that provides meaningful information, prevention, and intervention throughout their lives.

CATHERINE E. RICE, PH.D.

PREFACE

This book is the product of an interdisciplinary conference funded in 2014 by a grant from the U.S. Department of Health and Human Services, Agency for Health Care Research and Quality (1R13HS023035-01) and matching grants from Drexel University College of Nursing and Health Professions, Drexel University Online, and the A.J. Drexel Autism Institute. The purpose of the conference was to start a conversation among experts, professionals and consumers. We presumed that if we brought together healthcare providers to learn about and discuss these conversations it would stimulate new and creative approaches to the provision and coordination of medical care for people with autism spectrum disorder (ASD) across the lifespan. The conference provided a forum for the discussion of a research agenda to evaluate the outcomes of integrated care and policy efforts.

We hope that improving such coordination of care derived from creative problem solving will reduce miscommunication among providers, family members and patients, and control the confusion that compromises patient safety or delays in the delivery of needed services. We also hope that, over time, better integration of care will reduce costs, improve treatment outcomes, and improve the quality of life for people with ASD. This book continues the conversation and proposes ways to test these presumptions and affect changes.

We conceptualized this book as a service to our colleagues and a responsibility to our patients with autism spectrum disorder and their families. It satisfies a need for a clear, comprehensive collection of interdisciplinary perspectives on how to provide quality health care when a patient is also diagnosed with autism spectrum disorder (ASD). The conference had a key address, summarized by Doctor Catherine Rice in the Foreword. The book is divided into four sections that correspond with the four sessions of the conference and reflect the overarching need to understand the scope of the problem, consider different solutions, examine different environment and contextual factors, and recognize the need for research and policy changes. The chapters offer perspectives from leaders across multiple health care services and in public policy and research. The authors include nurses (women's health, primary care, urgent care), physicians (psychiatry, pediatrics, gerontology), educators, occupational therapists, physical therapists, epidemiologists, psychologists, public health professionals, and genetic counselors.

In Section 1, the chapters examine and explore the type and scope of the factors that contribute to the problem of providing comprehensive health care to people with ASD. In Chapter 1, I outline how a fragmented healthcare system results in rising costs and diminished quality of care. In Chapter 1, I call attention to urgent need for healthcare providers to learn to manage a complex set of symptoms and anticipate the potential side effects of polypharmacy. In Chapter 2, Michael J. Brenner, Kate E. Wallis and Jennifer A. Pinto-Martin discuss the epidemiology of ASD, the evolution of diagnostic codes, global prevalence, and proposed etiological theories. They make a convincing case for continuing research. In Chapter 3, Kathleen G. Freeman and Jennifer Harrison Elder share their personal and professional experience with ASD. They assert that healthcare providers must try to comprehend the complexity of the problem faced by parents of children and adults with ASD. They advocate for trying to comprehend the patient's and parent's reality, working closely with parents, and considering ways to prepare for medical visits. Care does not just flow from the healthcare provider to the patient. It is coextensive with sensations that flow from the environment in which care is delivered. In Chapter 4, Elizabeth Pfeiffer and Leah I. Stein Duker discuss sensory processing, anxiety and related obstacles to care. They offer anticipatory strategies and recommend environmental modifications to removed barriers to optimizing therapeutics. In Chapter 5, Paul A. Kettl considers the complexity of prescribing medications to the patient with ASD. He considers the comorbidities, side effects and polypharmacy, and introduces the reader to some promising pharmacotherapeutics presently under investigation.

Section 2 includes chapters that address the solutions to some of the problems described in Section 1, beginning with a framework to guide practice and research descried presented by Joan Rosen Bloch in Chapter 6. A broad view of healthcare services is used to point out the ways equity, effectiveness, and efficiency can be improved. In Chapter 7, services settings are further examined and the pediatric Medical Home is described as the exemplar for comprehensive care. The author, Renee Turchi, illustrates further the ways to provide patient and family centered care and how to engage community partners and how partnerships are key. In Chapter 8, James E. Connell, Margaret C. Souders and Connor M. Kerns extend the idea and apply the principles of the Medical Home to the adult ASD services. They share their Case Consultation Model as a way to address the complex challenges and needs of the adult population. Selecting optimal intervention from among a host of treatment options can be daunting for patients and family members. In Chapter 9, Jennifer Harrison Elder advises on how healthcare providers can assist parents and other family caregivers to best navigate the healthcare system and make informed circles. She offers advice on how to support family members and informal caregivers and summarizes the key instructional points when discussing complementary and alternative therapies. Genetic testing is becoming the standard of care in diagnosing cases of ASD. In Chapter 10, Marian Reiff and Surabhi Mulchandani share their expertise to explain first-line genetics testing, psychosocial implications, and practice implications. They offer recommendations for pre- and post-counseling and practice and policy changes.

The knowledge base of the health provider, the immediate environment, and other contextual factors such as social variables will have an effect on how health services can be integrated. These are explored in Section 3. In Chapter 11, Marcia R. Gardner describes how professional nurses conceptualize their role in the care of patients with ASD. She uncovers faculty and curriculum obstacles and offers her advice on designing training programs that are effective and innovative. In urban centers, emergency departments may be the principal source of care for patients without health insurance. In Chapter 12, Romy Nocera describes common medical emergencies among patients with ASD, along with the process for admitting, assessing, and designing treatment plans for urgent care. A consideration of core symptoms is necessary, and environmental modifications, along with appropriate triage questions, will enhance the benefit of inter-professional communication and help to insure a therapeutic encounter. Physical therapy is often prescribed for people with ASD to promote motor function and sensory modulations. In Chapter 13, Margaret E. O'Neil and Maria Fragela-Pinkham present a case study illustrating optimum integrated care from the perspective of the physical therapist. Section 3 is completed with Chapter 14 in which the author, Carl V. Tyler, Jr., describes how to use Big Data to direct quality improvement. He illustrates an analytic platform and its key functions and makes a convincing argument that these data can facilitate the integration of healthcare services.

Section 4 contains chapters offering perspectives on research, policy development, and the process for selecting patient outcomes to monitor. Judith Miller, Meghan N. Davignon, Terisa P. Gabrielsen, and Eron Y. Friedlaender begin the section with Chapter 15 in which they describe the characteristics of a good healthcare experience for a person with ASD. They advise that measuring and evaluating are essential components of care and can be guided by the application of an ecological systems perspective. They introduce various approaches to researching treatment choices and outcomes. In Chapter 6, Lindsay Shea, David S. Mandell, and Craig Newschaffer tackle the important issue of policy develop and systematic change. They outline policy issues related to Medicaid and insurance mandates as they pertain to ASD. The authors provide a model of success and strategies for engaging policy makers. Section 4 culminates with frequently asked questions and answers from the experts on the integration of healthcare for people with ASD.

Many important people contributed to the preparation of the book and the success of the conference. I am most grateful to my co-editor Kathleen Fisher for sharing her expert knowledge of caring for people with special needs, her attention to detail, and her untiring willingness to take on more responsibility. Doctor Jennifer Plumb was co-investigator on the grant, directed marketing efforts, and orchestrated the flow of questions and answers for Chapter 17. The moderators of each of four panel discussions lent their unique expertise and skill in fielding questions and guiding discussion. They were Mrs. Jean Ruttenberg, Dr. Diana Robins, Dr. Margaret O'Neil, and Dr. Paul Shattuck.

I wish to thank the conference committee, Kathy Freeman, Kartikeya Puranik, Margaret O'Neil, and Elizabeth Nolan, for the many roles they played and the marketing/advertising/website group from Drexel University College of Nursing and Health Profession (DU-CNHP). Included in this cohort are Laura Valenti, Wayne Miller, Christine Migeot, and Craig Schlanser. Also included are Anna Auch, Joan Bloch, Andrea Bricklin, Rebecca Charuk, Nicole Davis, Rachel Ewing, Janelle Gillis, Kirsten Glaser, Christina Klassis, Christine McAuliffe, Mary Kate O'Keefe, Jessica Rast, Margaret Rowen, Mahmoud Shurbaji, Laura Valenti, and John Zabinski. A special thanks goes to Doctor Fran Cornelius for help in establishing and enrolling students in the Post-baccalaureate Certificate Program in the Nursing Care of Autism Spectrum Disorder at DU-CNHP.

Finally, I am grateful to the following individuals for their support of the conference and support and advocacy for the larger, social endeavor to improve the quality of health care and the quality of life for people with ASD and their families. These advocates are: Mr. John A. Fry, President of Drexel University (DU); Dr. Gloria Ferraro Donnelly, Dean of the DU College of Nursing and Health Professions; Dr. Albert Rundio, Associate Dean for Post Licensure Nursing Programs at DU College of Nursing and Health Professions; Dr. Elizabeth Gonzalez, Doctoral Nursing Chair; and Dr. Craig Newschaffer, Director of the AJ Drexel Autism Institute.

E.G.

CONTENTS

Section 1
THE PROBLEM: SCOPE/BREADTH OF THE PROBLEM OF PROVIDING COMPREHENSIVE HEALTH CARE TO PEOPLE WITH ASD

Section 2
THE SOLUTIONS: EFFECTIVE, SAFE, COORDINATED CARE

Section 3
ENVIRONMENTS, SERVICES, AND CONTEXT

Section 4
MONITORING PATIENT OUTCOMES: RESEARCH AND POLICY DEVELOPMENT

INTEGRATED HEALTH CARE FOR PEOPLE WITH AUTISM SPECTRUM DISORDER

Section 1

THE PROBLEM: SCOPE/BREADTH OF THE PROBLEM OF PROVIDING COMPREHENSIVE HEALTH CARE TO PEOPLE WITH ASD

Chapter 1

INTEGRATING KNOWLEDGE OF AUTISM WITH COMPREHENSIVE HEALTH CARE

Ellen Giarelli

Health Care in a Fragmented System

The United States (US) has a fragmented healthcare system with limited primary care resources and a large uninsured population. According to the Institute of Medicine and the National Research Council (Woolf, Aron, Committee on Population of the Division of Behavioral and Social Sciences and Education, & Board on Population Health and Public Health Practice of the Institute of Medicine, 2013), the US health disadvantage is expressed as higher rates of chronic disease and mortality among adults and as higher rates of untimely death and injuries among adolescents and small children. One explanation for the health disadvantage of the US might be its deficiencies in the planning and delivery of health services. Another factor that diminishes the effectiveness of health care in the US is its disruptions in the care delivery process.

For many years, quality improvement programs and health services research have recognized that the fragmented nature of the US healthcare system, miscommunication, and incompatible information systems create lapses in care; oversights and errors; and unnecessary repetition of testing, treatment, and associated risks, because records of prior services are unavailable (Fineberg, 2012; Institute of Medicine & Committee on Public Health Strategies to Improve Health, 2012; Kohn, Corrigan, Donaldson, & Committee on Quality of Health Care in America, 2000). These problems exist for the general population and may be compounded for the patients with autism spectrum disorder (ASD).