I. Leslie Rubin · Joav Merrick
Donald E. Greydanus · Dilip R. Patel *Editors*

Health Care for People with Intellectual and Developmental Disabilities across the Lifespan

Springer

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Rubin and Crocker 3rd Edition

Springer

Editors
I. Leslie Rubin
Innovative Solutions for Disadvantage and Disability and Department of Pediatrics
Morehouse School of Medicine
Atlanta, GA, USA

Donald E. Greydanus
Department of Pediatric and Adolescent Medicine, Western Michigan University Homer Stryker MD School of Medicine
Western Michigan University
Kalamazoo, MI, USA

Joav Merrick
National Institute of Child Health and Human Development and Medical Services, Division for Developmental and Developmental Disabilities
Ministry of Social Affairs and Social Services
Jerusalem, Israel

Dilip R. Patel
Department of Pediatric and Adolescent Medicine, Western Michigan University Homer Stryker MD School of Medicine
Western Michigan University
Kalamazoo, MI, USA

ISBN 978-3-319-18095-3 ISBN 978-3-319-18096-0 (eBook)
DOI 10.1007/978-3-319-18096-0

Library of Congress Control Number: 2016938109

Printed on acid-free paper

This Springer imprint is published by Springer Nature
The registered company is Springer International Publishing AG Switzerland

Part I

Introduction

Foreword

It was my privilege to serve as the 16th US Surgeon General from 1998 to 2002. For three of those years, I also served as Assistant Secretary for Health (ASH) in the Department of Health and Human Services (DHHS). As ASH, I was able to lead the development of Healthy People 2010 (HP2010) – the nation's health plan for the decade. One of the two goals of HP 2010 was to improve the quality and years of healthy life. There are some specific objectives related to the need to improve the quality of life and experiences of persons with developmental disabilities throughout the lifespan. The second goal was that of eliminating disparities in health among different racial and ethnic groups as well as other groups who suffer disproportionately, such as persons with disabilities.

The HP2010 plan was released to the nation in January 2000, but it was not until March 2001 that I fully appreciated the significance of the goal of improving the quality of life of persons with developmental disabilities. It was then that I was invited to testify at a Senate Subcommittee Hearing in Anchorage, Alaska, chaired by Senator Ted Stevens and held in conjunction with the 2001 Special Olympics. At the Special Olympics, I was able to observe persons with developmental disabilities at their best, but also witness the tremendous unmet needs of this group of persons for health maintenance and healthcare. At the invitation of Dr. Timothy Shriver, son of Eunice Shriver (1921–2009), I had lunch with a group of parents of persons with developmental disabilities and listened to them detail their experiences with the current healthcare system. Their indictment of the healthcare system left me without speech or appetite.

In addition, a group of healthcare providers who served the Special Olympics and took care of patients with developmental disabilities in their own practices took me on rounds. During this session I observed some of the major health problems of this group ranging from decayed teeth and periodontal disease to severe cardiovascular disease at a young age. By the time I testified before Senator Steven's committee, I had changed my prepared speech to one in which I expressed concern and embarrassment for the health experience of persons with developmental disabilities, and I announced my intent to prepare and release a Surgeon General's Report on the healthcare needs of persons with developmental disabilities.

In October 2001, I held a Surgeon General's Listening Session on the topic of developmental disabilities and had the opportunity to listen to persons with developmental disabilities, their families, the caregivers, health professionals,

and policy makers. This listening session was followed in December 2001 by a Surgeon General's Conference on the health needs of children and adults with intellectual and developmental disabilities. It was out of that conference along with contributions from my colleagues at the National Institute for Child Health and Human Development that we were able to prepare our report. In February 2002, I had the opportunity to release what would be my last report as Surgeon General. It was entitled "Closing the gap: A national blueprint to improve the health of persons with mental retardation."

I am pleased that the findings, goals, and major actions recommended in that report are dealt with so well in this comprehensive textbook of healthcare for children and adults with intellectual and developmental disabilities. Thus, I will not repeat them in this statement. Clearly, the needs, challenges, and opportunities for intervention to enhance the health and well-being of persons with developmental disabilities are present throughout the lifespan. Optimally, care is provided with an appreciation for the complexity of challenges faced by the person with disabilities but also within the context of a dynamic family structure. Equally dynamic is the healthcare system upon which persons with disabilities rely for their care. Thus enhancement in the knowledge, the technologies, and systems available for care can dramatically impact life expectancy and quality of life for persons with developmental disabilities.

Yet there is not, and never will be, a substitute for the so-called medical home which provides a large portion of the care needed for persons with developmental disabilities. Moreover, this medical home coordinates access to all other care needed while maintaining meaningful and therapeutic relationships with the individuals and their families. A primary care or medical home still remains critical to quality healthcare for this population. But the care of persons with developmental disabilities also takes place in the context of community – a community not only of resources, but a community of knowledge, attitudes, and values, all important to the quality of life of persons with developmental disabilities.

I am pleased that an international community of experts have come together to create the third edition of this text dealing with the healthcare need of persons with intellectual and developmental disabilities. It is a very comprehensive, timely, and thorough report, bringing to bear the latest knowledge and technologies related to this field. Perhaps never before has this topic been dealt with so comprehensively and so insightfully.

Satcher Health Leadership Institute
Morehouse School of Medicine
Atlanta, GA, USA

David Satcher

Tribute: Tribute to the Pediatrician Allen C Crocker (1925–2011)

Introduction

This book is in a sense a tribute to my mentor, colleague, and friend who was my coeditor on the two previous editions of this book. It was a privilege for me to work with Allen and to learn from him how to think about health and well-being in the lives of individuals with intellectual and developmental disabilities and their families at a personal level as well as at the level of public health, public policy, and public responsibility. While Allen towered above his peers in his intellectual grasp of situations and in his productivity, he was an equal to his patients and their families in his compassion and in his poetry. He was universally appreciated and applauded.

He led a very productive and influential life and was clinically and socially active until his retirement at the age of 84 years. He left a legacy of papers, books, ideas, influences, enlightened students, and devoted admirers. Most significantly in this context is his influence relating to the spirit and much of the content of our two previous editions of this book and now, posthumously, on this 3rd edition of Rubin and Crocker's text on healthcare for children and adults with intellectual and developmental disabilities.

Background

I first met Allen Crocker in the spring of 1979, when I was on the faculty at the Department of Pediatrics, Case Western Reserve University School of Medicine as assistant professor in the Comprehensive Care Program (Comp Care) at the Cleveland Metropolitan General Hospital in Ohio. I had completed my fellowship in "care of the handicapped child" in the summer of 1978 and joined Comp Care. As part of my responsibility I was medical director of the Warrensville Developmental Center in Warrensville Ohio.

Comp Care was an interdisciplinary program with multidisciplinary clinics for children with cerebral palsy, spina bifida, craniofacial defects, and rheumatoid arthritis with other orthopedic, genetic, and neurological conditions and syndromes that required attention to the physical, medical, surgical, rehabilitation, and psychosocial aspects of the child and also the needs of the family. In addition, it had an inpatient service, where the children were admitted for medical complications and surgical procedures. The model was one that provided a comprehensive set of services that were well coordinated and family centered with a continuity of care – in essence, it embodied the concept of a medical home as we know it today [1, 2]. In addition, my involvement with the Warrensville Developmental Center and the group of approximately 200 adults with developmental disabilities provided me with the long-term perspective of how the lives of the children would play out as they matured to adulthood.

It was with this experience that I met Allen Crocker, in the spring of 1979 when he came to consult to the Department of Genetics on the etiological diagnosis of mental retardation. I was assigned to tell Allen about Comp Care and about the Warrensville Developmental Center. After the interview, Allen invited me to visit his program at the Boston Children's Hospital (BCH).

It was a sunny day in July 1979 when I visited the Developmental Evaluation Clinic (DEC) on the 10th floor of the Fegan Building at the BCH. Allen introduced me to his staff and had me tell them about what I was doing, and then we went for lunch. At lunch he offered me a position on his team with an academic appointment in the Harvard Medical School with half-time responsibility for "medical education" at the Wrentham State School (WSS) in Wrentham Massachusetts.

The Developmental Evaluation Clinic, Boston Children's Hospital and Harvard Medical School

The DEC was one of a national network of University Affiliated Programs (UAPs) that were originally funded in the late 1960s by Maternal and Child Health as a university-based interdisciplinary training center for professionals in the field of mental retardation (now known as intellectual and developmental disabilities). Before becoming director of the DEC, Allen had been working on inborn errors of metabolism. One of my favorite talks that Allen would give regularly was on the biochemistry, clinical features, and human aspects of children who had the variety of different syndromes associated

with inborn errors of metabolism. I believe that it was his work with the conditions associated with neurodevelopmental disabilities and "mental retardation" as well as his exceptional intellect and humanism that made him the ideal person for the position as director of the DEC.

By the time I joined the DEC in July of 1980, there was a sizable faculty and staff and a lively buzz of activity with large-scale interdisciplinary evaluations and a variety of other academic, research, and community programs and activities – the most notable of which was the Down Syndrome Clinic. Interestingly, although Allen was involved with many different groups of people, the world of Down syndrome seemed to resonate best with him. He appeared to bask in the reflected charm and beauty he saw in the children and adults with Down syndrome, and he in turn reflected his grace and poetry on everyone he met. This relationship is exemplified in his support of Gretchen Josephson, a young woman with Down syndrome, who had written poetry that she had embarrassedly hidden in boxes under her bed. Allen encouraged her to bring them to light and eventually helped her get them published, and he would often read them at special events [3].

Wrentham State School

One of my responsibilities was as director of medical education at the WSS, which was one of the large institutions for people with mental retardation in Massachusetts. In the first half of the twentieth century, "schools" were developed to educate children with physical, developmental, educational, or behavioral aberrations. At the time public schools in the USA did not admit any child who could not function adequately in the typical school environment. These special "schools" were often located far away from the mainstream of society, and depending on where they were, they might have had some agricultural or vocational element. Because there were limited resources at that time, a practice emerged among pediatricians to recommend to parents who had children born with congenital anomalies or who were diagnosed as having mental retardation or cerebral palsy that they place their children in one of these schools. Over time, the number of schools increased and the number of children in these schools also increased. Over the decades, the children became older and the quality of the services to these schools diminished, until the middle of the twentieth century when the institutions were run by medical personnel and provided custodial care in the most unimaginable of conditions. These conditions were exposed by academics, notably Burton Blatt in his famous book *Christmas in Purgatory* [4], as well as by professionals, journalists, and politicians – most notably the Kennedy family who had a daughter with a significant disability. In the early 1960s the Kennedy administration initiated an investigation into what was needed to provide appropriate healthcare, education, and socialization for people with "mental retardation." This resulted in the formation of the establishment of interdisciplinary clinical training programs (UAPs) and academic research programs (Mental Retardation Research Centers) and the establishment of the National Institute of Child Health and Human Development at NIH in 1962.

As a result of the poor quality of care that their children were receiving in the institutions, the parents initiated class action suits against the states. In response to the lawsuit, the State of Massachusetts contracted with the Children's Hospital to provide medical and therapeutic services to the WSS. Allen was the project director, and when the contract began in the 1970s, there were 2,000 individuals living at the WSS and organized services through physicians and mid-level practitioners from the Children's Hospital and from the Brigham and Women's Hospital to provide primary care and specialty outpatient and inpatient services.

When I arrived in 1980 there were 1,000 residents with a set of services that was of a high standard with a strong sense of learning from experience and the establishment of systems of care. Based on the experience of the academic clinicians and the knowledge gained over the years, Allen and I assembled a cohort of authors and published our first book together in 1989 called *Developmental Disabilities: Delivery of Medical Care for Children and Adults* [5]. This book proved to be the first of its kind to examine the medical care for adults with developmental disabilities. It also provided the field with a text from which to build clinical services and an academic discipline. In 2006 we published the 2nd edition, which was richer with an expanded scope and supplemented by clinical vignettes [6].

Allen, Career, Publications, and Awards

These two books are among the more than 20 books, 50 chapters, 60 original articles, and other writings including prefaces, proceedings of conferences, and articles in newspapers, magazines, and other periodicals of organizations as well as poetry that Allen has authored or edited in his lifetime. Allen was one of the first pediatric academic clinicians to embrace the impact of AIDS on the development of children and published a book on HIV infection and developmental disabilities in 1992 [7].

Allen began his academic career at the Massachusetts Institute of Technology, where he graduated in 1944 and then graduated from Harvard Medical School in 1948. He began his clinical training in pediatrics at the Children's Hospital in Boston in 1948 and continued at the Children's Hospital as associate in medicine and in a leadership position as director of the Developmental Evaluation Clinic from 1967 to 1993 and program director of the Institute for Community Inclusion from 1993 to 2009. Since 1982 he had a faculty appointment in the Harvard School of Public Health in Maternal and Child Health as well as in Society, Human Development, and Health. Allen was also on the boards of many local, regional, and national organizations and committees and often chaired these committees. He received more than 20 awards and has had awards named after him including the Allen C Crocker Award given at each annual meeting of the New England Regional Genetics Group, and a similar award is presented through the Massachusetts Down Syndrome Congress (MDSC) each year. In addition the

MDSC has a new fellowship for self-advocates. The Boston Children's Hospital has the Allen C Crocker Award for Clinical Excellence and Advocacy and in process is an Allen C Crocker Family Fellowship program in Massachusetts.

A Leader, a Pioneer, and a Humanist

In all, Allen C Crocker was a leader and a pioneer in the field of developmental disabilities and related fields. He set the tone and paved the way for many of us to follow and build upon – he was an active editor of all four editions of *Developmental-Behavioral Pediatrics* – the seminal text for the field [8].

But he was more than that. Allen was also sensitive, a humanist, a poet, and above all a family man. Every week he would display newspaper cuttings of a variety of topics relating to developmental disabilities and families from political pieces to human interest stories – these made for interesting reading while we were passing along the hallway outside his office.

His office was filled with his many awards as well as other notable tokens of his travels – most relating to individuals with developmental disabilities who he had admired. The most significant and interesting of all were the photographs of his three children. He would have a photograph of the group each year and arranged them in chronological order – so one would see them growing and developing into fine people and also see the changes in fashion over the years. This piece of his world gave him that humanity that is so often lacking in men of his greatness and was, unquestionably, part of his poetic sensibility that shaped his dealings with families and colleagues. He would never forget anyone's birthday and always recognize a particular positive trait or accomplishment about people.

Allen served in the US Army Medical Corps as a first lieutenant and captain from 1951 to 1953 and was stationed in Nuremberg, Germany, where he met his wife. Together they raised three children and were blessed with nine grandchildren. Every year Allen invited everyone to their family beach house in Gloucester on Cape Ann in Massachusetts for a "summer fling." This event was attended by all the staff and their families which gave everyone an opportunity to get to know each other in a more personal way, which made a difference with such a large number of people.

Allen liked to read stories and poetry every year in the lobby area of the clinic for the staff Christmas party. Everyone would sit around while he read a story. His reading brought the stories to life with a fresh relevance, and every year they would be different. The one I remember best was the story by O Henry entitled "The gift of the Magi" about a young married couple who were quite poor, but so in love with each other that they sacrificed their prized possessions in order to be able to give a gift to each other for Christmas [9]. Incidentally Allen was born on Christmas day!

My Last Visit and Interviews with Allen

We were fortunate to spend time with Allen on a snowy day in January 2011 in his daughter Elli's warm and gracious home in Newton, Massachusetts, in conversations that were recorded for posterity. Allen had chosen four people to interview him in intimate discussions:

- Ludwik Szymanski, MD, Child Psychiatrist, who he had known for 40 years – since the beginning of the formation of the Developmental Evaluation Clinic at Children's Hospital
- Leslie Rubin, MD, Developmental Pediatrician, who he had known for 30 years
- David Helm, PhD, ICI/LEND Director, who he had known for 20 years and now holds his position as director of the LEND program
- Brian Skotko MD, MPH, Pediatrician and Fellow in Genetics, who he had known for 10 years, first as a medical student and then as a colleague with a focus on Down syndrome

The set of interviews was captured on video and will be available for viewing through the Boston LEND program. In preparation for the set of interviews, Allen had prepared a one-page review which he entitled "Pediatric experience, 62 years on Longwood Avenue and Notes from a dynamic period in child care." He wrote as follows:

> Basic education at MIT, HMS, grad 48, 3 years houseofficership, and army four and then work. Asked to reflect on this half century special needs, apologies for personal orientation – useful to consider peaks
>
> - Enhancement of children's rights
> - Rise of parent advocacy
> - Gratitude to heroes and heroines
> - Inspiration in education
> - Federal leadership emerging
> - Decline in congregate living
> - Birth of developmental pediatrics
> - The role of Down Syndrome
> - Outreach to prevention
> - Agony of AIDS
> - Autism explodes
> - Special – premature, early intervention, adoption, therapy and genetics

His Importance for the Future of Children, Families, and Professionals

The following are some vignettes captured in an obituary in The Boston Globe, one of Allen's favorite newspapers, which illustrate the impact he had on people with whom he came into contact [10]:

> When Isaiah Lombardo was born nearly 16 years ago with Down syndrome, his mother looked to the future and saw only uncertainty. "I didn't know prenatally, so it was a surprise," Angela Lombardo said. "It was very overwhelming and scary."

> For the first couple of years, doctors cautioned her to anticipate the worst. Then she took Isaiah to Children's Hospital Boston, where Dr Allen C Crocker offered a very different perspective."Every other doctor would list all the things that could go wrong," Lombardo said. "He was the person who said, 'He's a wonderful little boy.' Dr Crocker was the first person who allowed families to celebrate, even though they had a child with a disability."
>
> "People with disabilities – or 'exceptionalities,' as Allen would often write – deserve respect from the communities that they enrich," Dr. Brian Skotko, a protégé who is now a Down syndrome specialist at Children's Hospital, said at Dr Crocker's memorial service Sunday. "He knew it. He believed it. He fought for it, and he motivated others to do the same, including me." "They may not all know it, but children with Down syndrome and other disabilities have more opportunities today because of Allen," Skotko said at Sunday's memorial service. "Parents fight fewer battles because Allen tore down walls."

In a 2006 interview with "Children's News," a publication at Children's Hospital, D. Crocker measured the distance traveled in his career. "Our success is symbolized by the way both pediatrics and the public feel about children with special needs," he said. "The little ones with Down syndrome around here are full of important personal successes. I think I can fairly claim that the families of children with Down syndrome are no longer grieving; they are celebrating."

Parents and children also benefited from one-on-one contact with a doctor who grinned with his patients, hugged mom and dad, and let everyone know things were going to be great.

> The kids were drawn to him because he was a different soul," Lombardo said. "Families felt a lot of peace when they left. They would come in scared, and he allowed them to leave happy and looking forward to the future. That's a huge gift.

The Gloucester Times, in the area where the Crockers had their summer home, stated on October 29, 2011:

> Allen was a lover of poetry, art, music, literature, oysters, wine, and nature (he could identify almost every native plant, marine invertebrate, and insect species) – and he liberally shared his passions with others. He found comfort and peace sitting on the deck in Gloucester with a view of Niles Pond and Brace Cove. Allen's lifetime motto (taken from his days as an Eagle Scout) was, "Leave the campsite better than you found it." This he certainly did. The world is better for his presence.

Allen's presence lives on within all of us and in the work that he has done and great changes he helped bring about. Thanks for everything you have given us, old friend!

Department of Pediatrics
Morehouse School of Medicine/Innovative Solutions for Disadvantage and Disability
776 Windsor Parkway, Atlanta, GA 30342, USA

Leslie I. Rubin
lrubi01@emory.edu

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About the Editors

Editors

Leslie Rubin M.D. is president and founder of the Innovative Solutions for Disadvantage and Disability (ISDD); research associate professor at the Department of Pediatrics, Morehouse School of Medicine in Atlanta, Georgia; Codirector of the Southeast Pediatric Environmental Health Unit at Emory University; and medical director of Developmental Pediatric Specialists, Atlanta, Georgia. He is originally from South Africa, where he trained in pediatrics. He came to the USA to specialize in neonatology and then in developmental pediatrics. He was initially at the hospital of the Case Western Reserve University in Cleveland, Ohio, from 1976 to 1980 and then moved to the Children's Hospital in Boston and the Harvard Medical School from 1980 to 1994. In July 1994 he moved to Atlanta, Georgia, as director of Developmental Pediatrics at Emory University and as medical director of the Marcus Center. Since 1998, he has been involved with the Southeast Pediatric Environmental Health Specialty Unit at Emory University, where he has integrated his understanding of developmental disabilities into the world of environmental health. In May 2004, he founded the Institute for the Study of Disadvantage and Disability (now Innovative Solutions for Disadvantage and Disability), which is dedicated to improving awareness and understanding of the relationship between social and economic disadvantage and disabilities in children. In September 2004, he left Emory University and joined the faculty of Morehouse School of Medicine. He is the recipient of the 2012 Calvin J Sia Award from the American Academy of Pediatrics for work on a Medical Home for Homeless Children and also through the ISDD of the 2013 Martin Luther King Jr Award from Emory University Business School and School of Public Health for the work of ISDD in improving the lives of children who grow up in circumstances of social and economic disadvantage. E-mail: lrubi01@emory.edu

Joav Merrick M.D., MMedSci, DMSc is professor of pediatrics, child health, and human development at the Division of Pediatrics, Hadassah Hebrew University Medical Center, Mt Scopus Campus, Jerusalem, Israel, and Kentucky Children's Hospital, University of Kentucky, Lexington, Kentucky, USA; professor of public health at the Center for Healthy Development, School of Public Health, Georgia State University, Atlanta, USA; the medical director of the Health Services, Division for Intellectual

and Developmental Disabilities, Ministry of Social Affairs and Social Services, Jerusalem; and the founder and director of the National Institute of Child Health and Human Development in Israel. Numerous publications in the field of pediatrics, child health and human development, rehabilitation, intellectual disability, disability, health, welfare, abuse, advocacy, quality of life, and prevention. Joav Merrick received the Peter Sabroe Child Award for outstanding work on behalf of Danish Children in 1985 and the International LEGO-Prize ("The Children's Nobel Prize") for an extraordinary contribution toward improvement in child welfare and well-being in 1987. E-mail: jmerrick@zahav.net.il

Donald E. Greydanus MD, Dr. HC (Athens), FAAP is professor and founding chair of the Department of Pediatric and Adolescent Medicine, as well as Pediatrics Program director at the Western Michigan University Homer Stryker MD School of Medicine (WMED), Kalamazoo, Michigan, USA. He is also professor of pediatrics and human development at Michigan State University College of Human Medicine (East Lansing, Michigan, USA) as well as clinical professor of pediatrics at MSU College of Osteopathic Medicine in East Lansing, Michigan, USA. He received the 1995 American Academy of Pediatrics' Adele D. Hofmann Award for "Distinguished Contributions in Adolescent Health," the 2000 Mayo Clinic Pediatrics Honored Alumnus Award for "National Contributions to the field of Pediatrics," and the 2003 William B Weil, Jr., MD Endowed Distinguished Pediatric Faculty Award from Michigan State University College of Medicine for "National and international recognition as well as exemplary scholarship in pediatrics." He received the 2004 Charles R Drew School of Medicine (Los Angeles, CA) Stellar Award for contributions to pediatric resident education and was awarded an honorary membership in the Indian Academy of Pediatrics—an honor granted to only a few pediatricians outside of India. He was the 2007–2010 Visiting Professor of Pediatrics at Athens University, Athens, Greece, and received the Michigan State University College of Human Medicine Outstanding Community Faculty Award in 2008. In 2010 he received the title of doctor honoris causa from the University of Athens (Greece) as a "distinguished scientist who through outstanding work has bestowed praise and credit on the field of adolescent medicine (ephebiatrics)." In 2010 he received the Outstanding Achievement in Adolescent Medicine Award from the Society for Adolescent Medicine "as a leading force in the field of adolescent medicine and health." He was past chair of the National Conference and Exhibition Planning Group (Committee on Scientific Meetings) of the American Academy of Pediatrics and member of the Pediatric Academic Societies' (SPR/PAS) Planning Committee (1998 to present). In 2011 he was elected to the Alpha Omega Alpha Honor Society (Faculty member) at Michigan State University College of Human Medicine, East Lansing, Michigan. He was former member of the Appeals Committee for the Pediatrics' Residency Review Committee (RRC) of the Accreditation Council for Graduate Medical Education (Chicago, IL) in both adolescent medicine and general pediatrics. He contributed numerous publications in adolescent health and lectureships in many countries on adolescent health. E-mail: donald.greydanus@med.wmich.edu

Dilip R. Patel MD, MBA, FAAP, FAACPDM, FACSM is professor in the Department of Pediatric and Adolescent Medicine, Western Michigan University Homer Stryker MD School of Medicine, Kalamazoo, and Department of Pediatrics and Human Development at the Michigan State University College of Human Medicine, East Lansing, Michigan, USA. He is a full time teaching faculty member in the Pediatric Residency Program at Western Michigan University School of Medicine, Kalamazoo, USA. Dr Patel has subspecialty training and interests in neurodevelopmental disabilities, developmental-behavioral pediatrics, adolescent medicine, and sports medicine. He has published numerous papers on wide-ranging topics in these areas and has edited several special symposia and books. E-mail: dilip.patel@med.wmich.edu

Contributors

Kruti Acharya Department of Disability and Human Development, College of Applied Health Sciences, University of Illinois at Chicago, Chicago, IL, USA

Elizabeth Adler Research and Training Center on Community LivingUniversity of Minnesota, Minneapolis, MN, USA

Randell C. Alexander Department of Pediatrics, University of Florida, Jacksonville, FL, USA

Fatis Altintas Department of Anesthesiology and Reanimation, Cerrahpasa Medical School, University of Istanbul, Fatih, Istanbul, Turkey

Norberto Alvarez Department of Neurology, Children's Hospital Boston, Boston, MA, USA

Justin Alvey Department of Pediatrics, University of Utah, Salt Lake City, UT, USA

Lynda Lahti Anderson Institute on Community Integration, University of Minnesota, Minneapolis, MN, USA

Maria de los Angeles Paul Department of Pediatrics, Facultad de Medicina, Pontificia Universidad Catolica de Chile, Santiago, Chile

Jack L. Arbiser Department of Dermatology, Emory University School of Medicine, Atlanta, GA, USA

Dermatology, Atlanta VA Medical Center, Decatur, GA, USA

Julie Arndt Research and Training Center on Community Living, University of Minnesota, Minneapolis, MNUSA

Orhan Atay Neurogastroenterology Motility Program, Division of Pediatric Gastroenterology, Children's Hospital of The King's Daughters, Norfolk, VA, USA

Naira Avetisyan Council of Europe Office in Yereva, Erebuni Plaza Business Center, Yerevan, Armenia

Chantel C. Barney Department of the Medical Director, Gillette Children's Specialty Healthcare, St. Paul, MN, USA

Jarrett Barnhill Department of Psychiatry, University of North Carolina School of Medicine, Chapel Hill, NC, USA

Christine Hoffner Barthold Graduate School of Education, George Mason University, Fairfax, VA, USA

Joan B. Beasley University of New Hampshire, Durham, NH, USA

The Center for START Services, Institute on Disability/UCED**,** Concord**,** NH**,** USA

John L. Belew Gillette Children's Specialty Healthcare, St. Paul, MN, USA

Elana M. Bern Division of Pediatric Gastroenterology, Nutrition and Hepatology, Boston Children's Hospital, Boston, MA, USA

Harvard Medical School**,** Boston**,** MA**,** USA

Lynda Brown Bersani Greater Albany Public Schools, Albany, ORUSA

Ann E. Borreson Division of Occupational Science and Occupational Therapy, Ostrow School of Dentistry, University of Southern California, Los Angeles, CA, USA

Jared Bourke Modbury Hospital, Modbury, SA, Australia

Karen M. Bovid Department of Orthopaedic Surgery, Western Michigan University School of Medicine, Kalamazoo, MI, USA

Theresa Broda Solution-s, Ottawa, ON, Canada

Marisa C. Brown Georgetown University Center for Child and Human Development, University Center for Excellence in Developmental Disabilities, Washington, DC, USA

Roy I. Brown School of Child and Youth Care, University of Victoria, Victoria, BC, Canada

Kim A. Bullock Department of Family Medicine, Boston University, Boston, MA, USA

Joshua Burns University of Sydney, Sydney, NSW, Australia

Ozlem S. Cakmakkaya Department of Anesthesiology and Reanimation, Cerrahpasa Medical School, University of Istanbul, Fatih, Istanbul, Turkey

Eliezer Carmeli Department of Physical Therapy, Faculty of Social Welfare and Health Sciences, University of Haifa, Haifa, Israel

Rosemary M. Caron Department of Health Management and Policy, College of Health and Human Services, University of New Hampshire, Durham, NH, USA

Jessica M. Cassidy Research and Training Center on Community Living, University of Minnesota, Minneapolis, MN, USA

Ian Casson Department of Family Medicine, Queen's University, Kingston, ON, Canada

Rachel-Marie A. Cazeau Section of Endocrinology, Metabolism and Diabetes, Nationwide Children's Hospital, Wexner Medical Center at The Ohio State University, Columbus, OH, USA

Sharon A. Cermak Division of Occupational Science and Occupational Therapy, Ostrow School of Dentistry, University of Southern California, Los Angele, CA, USA

Department of Pediatrics, University of Southern California Keck School of Medicine, Los Angeles, CA, USA

Lauren R. Charlot UMass ID/MH Multidisciplinary Evaluation Team, Worcester, MA, USA

UMass Memorial Medical Center, Worcester, MA, USA

Joni Charme Office of Public Health Preparedness and Response, Centers for Disease Control and Prevention, Atlanta, GA, USA

Tom Cheetham Health Services, Tennessee Department of Intellectual and Developmental Disabilities, Nashville, TN, USA

Tennessee Department of Children's Services, Office of Child Health, Nashville, TN, USA

Peter Chung Mattel Children's Hospital, University of California Los Angeles, Los Angeles, CA, USA

Jeff Clark Wayne State University School of Medicine, Detroit, MI, USA

Pediatric Critical Care Medicine, Children's Hospital of Michigan, Detroit, MI, USA

Fleur-Michelle M. Coiffait Child Development Psychology Service, The Den, Chesterfield Royal Hospital, Chesterfield, UK

Staeshe Collins Riverdale, GA, USA

James W. Conroy Center for Outcome Analysis, Havertown, PA, USA

Robert Conway Department of Pediatrics, Children's Hospital of Michigan, Wayne State University School of Medicine, Detroit, MI, USA

Stephen Corbin Special Olympics, Inc, Washington, DC, USA

John M. Costello Department of Otolaryngology, Boston Children's Hospital, Waltham, MA, USA

Michele Cracchiola Discovering Abilities Inc., Okeechobee, FL, USA

Daniel Crimmins Center for Leadership in Disability and the GaLEND Program, School of Public Health, Georgia State University, Atlanta, GA, USA

Joseph F. Cubells Department of Human Genetics and Emory Autism Center, Department of Psychiatry and Behavioral Sciences, Emory University School of Medicine, Atlanta, GA, USA

Steven J. Dale National Children's Center, Washington, DC, USA

Ellen Datner Frances L Loeb Child Protection and Development Center, Bellevue Hospital, New York, NY, USA

H. Dele Davies University of Nebraska Medical Center, Omaha, NE, USA

Daniel K. Davies AbleLink Technologies Inc, Colorado Springs, CO, USA

Robert W. Davis Centre for Developmental Disability Health Victoria, Monash Health Community, Dandenong, VIC, Australia

Catherine de Haas Cheshire, UK

Alexis Deavenport-Saman CPH Department of Pediatrics, Children's Hospital Los Angeles, Los Angeles, CA, USA

Anja Declercq LUCAS and Center for Sociological Research, Leuven, Belgium, Neuropsychiatry, The Greenfields, Birmingham, UK

Geoffrey R. DeTolve Newborn Hospitalist Service, Kalamazoo, MI, USA

Gary Diamond Institute of Child Development and Neurology, Schneider Children's Medical Center, Petah-Tiqva, Israel

Julie Dini Life Without Barriers, Netley, Australia

Valerie Dobie Adelaide, SA, Australia

Colleen Dodich Department of Pediatric and Adolescent Medicine, Western Michigan University Homer Stryker MD School of Medicine, Kalamazoo, MI, USA

Kenneth J. Dooley Children's Healthcare of Atlanta, Sibley Heart Center Cardiology, Emory University School of Medicine, Atlanta, GA, USA

Deborah Dreyfus Department of Family Medicine, Boston University, Boston, MA, USA

Linda R. Edwards College of Medicine, University of Florida, Jacksonville, FL, USA

Marc Emmerich Commonwealth Community Care, Boston Medical Center, Boston, MA, USA

David A. Ervin The Resource Exchange, Inc., Colorado Springs, CO, USA

Amy N. Esler Research and Training Center on Community LivingUniversity of Minnesota, Minneapolis, MN, USA

Lucille Esralew Consultant to New Jersey State DD Centers, Lumberton, NJ, USA

Angela Evans La Trobe University, Melbourne, Australia, AUT University, Adelaide, SA, Australia

Frans V.P.M. Ewals Department of General Practice, Rotterdam, The Netherlands

Fabrizio Fea Rehabilitation Centre for Persons with Disabilites, Associazione Scuola Viva Onlus, Rome, Italy

Ilan Feldberg Division for Intellectual and Developmental Disabilities, Ministry of Social Affairs and Social Services, Jerusalem, Israel

Jill Ferrari University of East London, London, UK

Cynthia Feucht Borgess Ambulatory Care, Ferris State University, College of Pharmacy, Kalamazoo, MI, USA

Jeffery A. Foran Department of Environmental Studies, California State University Sacramento, Sacramento, CA, USA

Sheridan Forster Centre for Developmental Disability Health Victoria, School of Primary Health Care, OMNICO, Business Centre Monash, Notting Hill, VIC, Australia

Michael H. Fox Division of Human Development and Disability, Centers for Disease Control and Prevention, Atlanta, GA, USA

Laura E. Fox Adjunct Faculty George Mason University School of Nursing, Private Practice-Fox Associates, LLC, Fairfax Station, VA, USA

Robin I. Friedlander Developmental Disabilities Mental Health Services, Vancouver Coastal Health Authority and Fraser Health Authority, Department of Psychiatry, University of British Columbia, BC Childrens Hospital, Neuropsychiatry, Vancouver, BC, Canada

Sandra L. Friedman Neurodevelopmental Behavioral Pediatrics, University of Colorado School of Medicine, Denver, CO, USA

Jennifer Fulbright Beaumont Cancer Genetics Program, Royal Oak, MI, USA

Satish Chandra Girimaji Department of Child and Adolescent Psychiatry, National Institute of Mental Health and Neuro Sciences (NIMHANS), Bangalore, India

Laurie Glader Harvard Medical School, Boston Children's Hospital, Boston, MA, USA

Thomas Graf Population Health and Longitudinal Care Service Lines, Geisinger Health System, Danville, PA, USA

J. Carolyn Graff Boling Center for Developmental Disabilities, University of Tennessee Health Science Center, Memphis, TN, USA

Donald E. Greydanus Department of Pediatric and Adolescent Medicine, Western Michigan University Homer Stryker MD School of Medicine, Kalamazoo, MI, USA

Liz Grier Department of Family Medicine, Queen's University, Kingston, ON, Canada

Stephanie Griese Office of Public Health Preparedness and Response, Centers for Disease Control and Prevention, Atlanta, GA, USA

Laura Gwatkin Nevill Hall Hospital, Monmouthshire, Wales, UK

Jason C. Hadley McKay-Dee Dermatology and Plastic Surgery, Ogden, UT, USA

Randi J. Hagerman MIND Institute, Fragile X Research, UC Davis Health System, Sacramento, CA, USA

Joan Earle Hahn Keene State College, Nursing Program, Keene, NH, USA

Ayelet Halevy Pediatric Neurology Unit, Schneider Children's Medical Center Israel, Sackler Faculty of Medicine, Tel Aviv University, Petah Tikva, Israel

Emma Hare MIND Institute, UC Davis Health System, Sacramento, CA, USA

Susan M. Havercamp Department of Psychiatry and Psychology, The Ohio State University Nisonger Center, UCEDD, Columbus, OH, USA

Akilah Heggs School of Public Health, Georgia State University, Center for Leadership in Disability, Atlanta, GA, USA

Tamar Heller Department of Disability and Human Development, College of Applied Health Sciences, University of Illinois at Chicago, Chicago, IL, USA

David T. Helm Leadership Education in Neurodevelopmental and Related Disabilities (LEND Program), Institute for Community Inclusion, Boston Children's Hospital, Boston, MA, USA

Brian Hennen Dalhousie University, Dartmouth, NS, Canada

Koen Hermans LUCAS and Center for Sociological Research, Leuven, Belgium

Amy Hewitt Research and Training Center on Community Living, University of Minnesota, Minneapolis, MN, USA

Candace Hind Faculty of Arts, Humanities and Social Sciences, Drama in Education and Community, School of Dramatic Art, University of Windsor, Windsor, ON, Canada

Matthew Holder Special Olympics Inc, Washington, DC, USA

Matt Hoghton Clevedon Riverside Group, North Somerset, UK

Clinical Innovation and Research Centre CIRC, The Royal College of General Practitioners, London, UK

Sydney Holmes Faculty of Arts, Humanities and Social Sciences, Drama in Education and Community, School of Dramatic Art, University of Windsor, Windsor, ON, Canada

Bill Howard Office of Public Health Preparedness and Response, Centers for Disease Control and Prevention, Atlanta, GA, USA

Maeve Howett Southeast Pediatric Environmental Health Specialty Unit, Emory University, Atlanta, GA, USA

Kelly Hsieh Rehabilitation Research and Training Center on Developmental Disabilities and Health, Department of Disability and Human Development, University of Illinois at Chicago, Chicago, IL, USA

Sylvia A. Huisman Prinsenstichting, Purmerend, The Netherlands

Bita Imam Department of Physical Therapy, Faculty of Social Welfare and Health Sciences, University of Haifa, Haifa, Israel

Robert A. Jacobs USC UCEDD, Children's Hospital Los Angeles, Los Angeles, CA, USA

Matthew P. Janicki Consultant to New Jersey State DD Centers, Lumberton, NJ, USA

Nancy S. Jokinen School of Social Work, University of Northern British Columbia, Prince George, BC, Canada

Laura Jones Division of Physical Medicine and Rehabilitation, Cincinnati Children's Hospital Medical Center, Cincinnati, OH, USA

Jessica Jones Ongwanada, Kingston, ON, Canada

Walid Kaddan Pediatric Neuro-Oncology Unit, Schneider Children's Medical Center of Israel, Sackler Faculty of Medicine, Tel Aviv University, Petah Tikva, Israel

Manmohan K. Kamboj Section of Endocrinology, Metabolism and Diabetes, Nationwide Children's Hospital, Wexner Medical Center at The Ohio State University, Columbus, OH, USA

Isack Kandel Maaleh Shomron, Lev Shomron, Israel

Shibani Kanungo Division of Metabolic Genetics, Janet Weis Children's Hospital, Geisinger Health System, Danville, PA, USA

Markus Kaski Rinnekoti Foundation (emer.), Vihti, Finland

Seth M. Keller Consultant to New Jersey State DD Centers, Lumberton, NJ, USA

Kathi J. Kemper Center for Integrative Health and Wellness, Ohio State University Wexner Medical Center, College of Medicine, Columbus, OH, USA

Fran D. Kendall Virtual Medical Practice, LLC, Atlanta, GA, USA

Rima Khasawneh Division of Pediatric Infectious Diseases, University of Nebraska Medical Center, Omaha, NE, USA

Joseph M. Klancnik Developmental Disabilities Mental Health Services, Vancouver Coastal Health Authority and Fraser Health Authority, Department of Psychiatry, University of British Columbia, BC Childrens Hospital, Neuropsychiatry, Vancouver, BC, Canada

Ann Klein The Center for START Services, Institute on Disability/UCED, Concord, NH, USA

Sarah L. Klemm Spectrum Health Medical Genetics, Grand Rapids, MI, USA

Chris Kochtitzky Program Development, Centers for Disease Control and Prevention, Division of Emergency and Environment Health Services, Atlanta, GA, USA

John Vijay Sagar Kommu Department of Child and Adolescent Psychiatry, National Institute of Mental Health and Neuro Sciences (NIMHANS), Bangalore, India

Osnat Konen Pediatric MRI Unit, Schneider Children's Medical Center Israel, Sackler Faculty of Medicine, Tel Aviv University, Petah Tikva, Israel

Bruce R. Korf Department of Genetics, Heflin Center for Genomic Sciences, University of Alabama at Birmingham, Birmingham, AL, USA

Gloria L. Krahn College of Public Health and Human Sciences, Oregon State University, Corvallis, OR, USA

Margaret R. Kyrkou Disability and Community Inclusion, School of Medicine, Flinders University, Adelaide, SA, Australia

Sheryl A. Larson Institute on Community Integration, University of Minnesota, Minneapolis, MN, USA

Ben M.F. Law Department of Social Work and Social Administration, The Jockey Club Tober, 5/f, The University of Hong Kong, Hong Kong, China

Leslie P. Lawley Department of Dermatology, Emory University School of Medicine, Atlanta, GA, USA

Mitchel Leavitt Emory Center For Rehabilitation Medicine, Emory University School of Medicine, Atlanta, GA, USA

Judith M. LeBlanc Department of Applied Behavioral Sciences, University of Kansas, Lawrence, KS, USA

Alexandra T. Leedham Learning Disability Child and Adolescent Mental Health Service (LD CAMHS), The Den, Chesterfield Royal Hospital, Chesterfield, UK

Brandi Lindsey School of Nursing, Middle Tennessee State University, Murfreesboro, TN, USA

Peter Lindsay Aireborough Family Practice, Silver Lane Surgery, Leeds, UK

Macarena Lizama Department of Pediatrics, Facultad de Medicina, Pontificia Universidad Catolica de Chile, Santiago, Chile

Alvin Loh Department of Pediatrics, University of Toronto, Surrey Place Centre, Toronto, ON, Canada

Donald J. Lollar Department of Public Health and Preventive Medicine, School of Medicine

University Center for Excellence in Developmental Disabilities (UCEDD)

Institute on Development and Disability, Oregon Health and Science University, Portland, OR, USA

Meir Lotan Department of Physical Therapy, School of Health Sciences, Ariel University, Ariel, Israel

Reymundo Lozano UC Davis Health System, Sacramento, CA, USA

James K. Luiselli The May Institute Inc., Randolph, MA, USA

Patricia Navas Macho Department of Psychiatry and Psychology, The Ohio State University Nisonger Center, UCEDD, Columbus, OH, USA

Robert William Marion Department of Pediatrics, Division of Medical Genetics, Children's Hospital at Montefiore, Albert Einstein College of Medicine, Bronx, NY, USA

Liliana Mayo Centro Ann Sullivan del Peru – CASP, San Miguel, Lima, Peru

Monica McCaffrey Sibs, Meadowfield, Oxenhope, West Yorkshire, UK

Robert P. McCaffrey Fitmatters, Inc., Newmarket, NH, USA

Charles A. McCaslin Division of Pediatric Pulmonary and Sleep Medicine, Cystic Fibrosis Care Center, Helen DeVos Women and Children's Health Center, Grand Rapids, MI, USA

Hilary H. McClafferty Pediatric Integrative Medicine in Residency, Arizona Center for Integrative MedicineUniversity of Arizona, Tucson, AZ, USA

Bruce McCreary Ongwanada, Kingston, ON, Canada

Karen McKenzie NHS Lothian, Community Child Health, Royal Hospital for Sick Children, Edinburgh, UK

Michael McWay Department of Pediatric and Adolescent Medicine, Western Michigan University Homer Stryker MD School of Medicine, Kalamazoo, MI, USA

Dale C. Strasser Department of Rehabilitation Medicine, Emory University School of Medicine, Atlanta, GA, USA

Hylton Menz La Trobe University, Melbourne, VIC, Australia

Raun D. Melmed Melmed Center, Scottsdale, AZ, USA

Joav Merrick Division for Intellectual and Developmental Disabilities, Ministry of Social Affairs and Social Services, Jerusalem, Israel

Aviva Mimouni-Bloch Pediatric Neurology and Developmental Unit, Loewenstein Rehabilitation Hospital, Sackler Faculty of Medicine, Raanana, Israel

Laura Minando Department of Otolaryngology & Communication Enhancement, Boston Children's Hospital, Boston, MA, USA

Rosario Moore Department of Pediatrics, Facultad de Medicina, Pontificia Universidad Catolica de Chile, Santiago, Chile

Mohammed Morad Yaski Community Medical Center, Ben Gurion University of the Negev, Clalit Health Services, Beer-Sheva, Israel

Melinda J. Morin Roundtable on Value and Science-Driven Health Care, Institute of Medicine, Washington, DC, USA

Stewart Morrison University of East London, London, UK

Brenda Liz Muñoz Duluth, GA, USA

Dawna Torres Mughal Morosky College of Health Professions and Sciences, Gannon University, Erie, PA, USA

Kerim M. Munir University Center for Excellence in Developmental Disabilities, Division of Developmental Medicine, Boston Children's Hospital, Boston, MA, USA

Shannon Munteanu La Trobe University, Melbourne, VIC, Australia

Nancy Murphy Comprehensive Care Program, Department of Pediatrics, University of Utah, Salt Lake City, UT, USA

Wendy M. Nehring College of Nursing, East Tennessee State University, Johnson City, TN, USA

Thomas Nerney National Center on Self-Determination, Wayne, MI, USA

Rose E. Nevill Department of Psychology, The Ohio State University Nisonger Center, UCEDD, Columbus, OH, USA

Ullanda Niel Scarborough Centre for Healthy Communities, Scarborough, ON, Canada

Nikolaos Nikolopoulos La Trobe University, Melbourne, VIC, Australia

Janice Nodvin Urban Family Practice Associates, Marietta, GA, USA

Jacqueline A. Noonan Department of Pediatrics, Division of Cardiology, University of Kentucky, KY Children's Hospital, Lexington, KY, USA

Patricia Novak Professional Child Development Associates, Pasadena, CA, USA

David O'Hara Institute for Human Development, University Center for Excellence in Developmental Disabilities, Valhalla, NY, USA

Tim F. Oberlander Child and Family Research Institute, University of British Columbia, Vancouver, BC, Canada

Jeffrey K. Okamoto Hawaii Department of Health, University of Hawaii at Manoa, Honolulu, HI, USA

Hatim A. Omar Division of Adolescent Medicine, Department of Pediatrics, University of Kentucky College of Medicine, Lexington, KY, USA

Division of Adolescent Medicine and Young Parents Program, Department of Pediatrics, Kentucky Children's Hospital, Lexington, KY, USA

Priscilla S. Osborne LEND Program, Boston Children's Hospital, Boston, MA, USA

Vincent J. Palusci New York University School of Medicine, Bellevue Hospital Center, New York, NY, USA

Lindsey Partington MIND Institute, Fragile X Research, UC Davis Health System, Sacramento, CA, USA

Dilip R. Patel Department of Pediatric and Adolescent Medicine, Western Michigan University Homer Stryker MD School of Medicine, Kalamazoo, MI, USA

Georgina Peacock National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention, Atlanta, GA, USA

Alan K. Percy Civitan International Research Center, University of Alabama at Birmingham, Birmingham, AL, USA

Elaine Maria Pereira Department of Pediatrics, Division of Medical Genetics, Children's Hospital at Montefiore, Montefiore Medical Center, Bronx, NY, USA

Elizabeth A. Perkins Florida Center for Inclusive Communities, Department of Child and Family Studies, College of Behavioral and Community Sciences, University of South Florida, Tampa, FL, USA

Rande Peyton Research and Training Center on Community Living, University of Minnesota, Minneapolis, MN, USA

Randall A. Phelps Child Development and Rehabilitation Center, Institute on Development and Disability, Oregon Health and Science University, Eugene, OR, USA

LaShawnDa Pittman Department of American Ethnic Studies, Faculty Affiliate, West Coast Poverty Center, University of Washington, Seattle, WA, USA

Barbara Rose Pober Department of Medical Sciences, The Frank H Netter School of Medicine, Quinnipiac University, North Haven, CT, USA

Department of Pediatrics, Massachusetts General Hospital, Boston, MA, USA

Brian P. Pollack Department of Dermatology, Emory University School of Medicine, Atlanta, GA, USA

Dermatology, Atlanta VA Medical Center, Decatur, GA, USA

Elizabeth Poplawski Pediatric Physiatrist, Children's Healthcare of Atlanta, Atanta, GA, USA

Teodor T. Postolache Mood and Anxiety Program, Department of Psychiatry, University of Maryland School of Medicine, Baltimore, MD, USA

Vee P. Prasher Neuropsychiatry, The Greenfields, Birmingham, UK

Helen D. Pratt Department of Pediatric and Adolescent Medicine, Western Michigan University Homer Stryker MD School of Medicine, Kalamazoo, MI, USA

Marlene Pryson Department of Pediatric and Adolescent Medicine, Western Michigan University Homer Stryker MD School of Medicine, Kalamazoo, MI, USA

Uttam K. Raheja Psychiatry Residency Training Program, Saint Elizabeths Hospital, Washington, DC, USA

Vandana Raman Division of Pediatric Endocrinology, Department of Pediatrics, University of Utah School of Medicine, Salt Lake City, UT, USA

Stacey Ramirez Center for Leadership in Diversity, GaLEND Faculty, Georgia State University, Atlanta, GA, USA

Paula D. Ravin Department of Neurology, Movement Disorder Center, UMass Memorial Medical Center, University Campus, Worcester, MA, USA

Alya Reeve Continuum of Care, University of New Mexico Health Sciences Center, Albuquerque, NM, USA

Cheryl Rhodes Marcus Autism Center, Children's Healthcare of Atlanta, Atlanta, GA, USA

Tonya Rich Research and Training Center on Community Living, University of Minnesota, Minneapolis, MN, USA

James H. Rimmer Health Promotion and Rehabilitation Sciences, University of Alabama at Birmingham, Birmingham, AL, USA

I. Leslie Rubin Department of Pediatrics, Morehouse School of Medicine and President, Innovative Solutions for Disadvantage and Disability, Atlanta, GA, USA

Innovative Solutions for Disadvantage and Disability, Atlanta, GA, USA

Ruth Ryan Department of Nursing and Midwifery, Faculty of Education and Health Sciences, North Bank Campus, University of Limerick, Limerick, Ireland

Preethy S. Samuel Department of Health Care Sciences, EACPHS, Wayne State University, Detroit, MI, USA

Tina Sarkar Center for Leadership in Disability (CLD), Georgia State University, Atlanta, GA, USA

Abigail Schindler Department of Disability and Human Development, College of Applied Health Sciences, University of Illinois at Chicago, Chicago, IL, USA

John Norman Schuen Division of Pediatric Pulmonary and Sleep Medicine, Cystic Fibrosis Care Center, Helen DeVos Women and Children's Health Center, Grand Rapids, MI, USA

Haleigh M. Scott Department of Psychology, The Ohio State University Nisonger Center, UCEDD, Columbus, OH, USA

Howard C. Shane Department of Otolaryngology, Boston Children's Hospital, Waltham, MA, USA

Shiva Sharma Pediatric Cardiology Services, Atlanta, GA, USA

Mahesh Sharman Michigan State University College of Human Medicine, Michigan State University, East Lansing, MI, USA

Pediatric Intensive Care Unit, Hurley Medical Center, Flint, MI, USA

Daniel T.L. Shek Faculty of Health and Social Sciences, Department of Applied Social Sciences, The Hong Kong Polytechnic University, Hong Kong, China

Laura Shewan Chesterfield Royal Hospital NHS Foundation Trust, The Den, Chesterfield Royal Hospital, Chesterfield, UK

Maurice G. Sholas Sholas Medical Consulting, LLC, New Orleans, LA, USA

Brian G. Skotko Division of Genetics, Department of Pediatrics, Massachusetts General Hospital, Boston, MA, USA

Harvard Medical School, Boston, MA, USA

Kathryn R.N. Smith Children's Hospital Los Angeles, Los Angeles, CA, USA

Peter J. Smith Department of Pediatrics, The University of Chicago, Chicago, IL, USA

Neelkamal S. Soares Neurodevelopmental Pediatrics, Janet Weis Children's Hospital, Geisinger Health System, Lewisburg, PA, USA

Mike Stawski The Outpatient Unit for Neurodevelopmental Psychiatry, Department of Psychological Medicine, Schneider Children's Medical Center in Israel, Petach-Tikva, Israel

Sorah Stein Department of Psychology, Indiana University South Bend, South Bend, IN, USA

Steven E. Stock AbleLink Technologies Inc, Colorado Springs, CO, USA

Stephanie J. Stockburger Division of Adolescent Medicine, Department of Pediatrics, University of Kentucky, Lexington, KY, USA

Dale C. Strasser Department of Rehabilitation Medicine, Emory University School of Medicine, Atlanta, GA, USA

Jenna L. Streicher Department of Dermatology, Emory University School of Medicine, Atlanta, GA, USA

Craig Strohmeier Kennedy Krieger Institute and the Johns Hopkins University School of Medicine, Baltimore, MD, USA

Sheri T. Stronach Research and Training Center on Community Living, University of Minnesota, Minneapolis, MN, USA

Shigeru Suemitsu Kawasaki University of Medical Welfare, Kurashiki, Okayama, Japan

Stephen B. Sulkes Golisano Children's Hospital, University of Rochester Medical Center, School of Medicine and Dentistry, Rochester, NY, USA

Frank J. Symons Department of Educational Psychology, University of Minnesota, Minneapolis, MN, USA

Cora M. Taylor Autism and Developmental Medicine Institute, Geisinger Health System, Lewisburg, PA, USA

Ariel Tenenbaum Down Syndrome Center Jerusalem, Division of Pediatrics, Hadassah University Medical Center, Jerusalem, Israel

Mitchell Tepper Atlanta, GA, USA

Helga V. Toriello Department of Human Development and Pediatrics, College of Human Medicine, Michigan State University, Grand Rapids, MI, USA

Ekaterini Tsilou Obstetric and Pediatric Pharmacology and Therapeutics Branch, The Eunice Kennedy Shriver National Institute of Child Health and Human Development, NIH, Bethesda, MD, USA

Christopher A. Tullis Georgia State University, Atlanta, GA, USA

Carl V. Tyler Geriatric Education and Research, Fairview Hospital/ Cleveland Clinic Family Medicine Residency Program, Fairview Hospital, Cleveland, OH, USA

Susumu Uehara Kawasaki University of Medical Welfare, Okayama, Japan

Peter Uldall Department of Paediatrics and Adolescent Medicine, Rigshospitalet, Copenhagen, Denmark

Hardeep Uppal Neuropsychiatry, The Greenfields, Birmingham, UK

Alex Van Speybroeck Department of Pediatrics, Children's Hospital Los Angeles, Los Angeles, CAUSA

Patricia M. Valenzuela Department of Pediatrics, Facultad de Medicina, Pontificia Universidad Catolica de Chile, Santiago, Chile

Abraham J. Valkenburg Erasmus University Medical Center – Sophia Children's Hospital, Rotterdam, The Netherlands

Søren Ventegodt Quality of Life Research Center, Copenhagen V, Denmark

Jakob Volther Residential Care, Søborg, Denmark

Joshua Vova Children's Rehabilitation Associates, Children's Healthcare of Atlanta, Atlanta, GA, USA

Jillian Wallen College of Dentistry, Department of Growth and Development, University of Nebraska Medical Center, Omaha, NE, USA

Department of Growth and Development, Advanced Specialty Education Program in Pediatric Dentistry, Special Pediatric Center, Omaha, NE, USA

Tom Walsh Flinders University, Adelaide, SA, Australia

Julian Wan Department of Urology, University of Michigan, Ann Arbor, MI, USA

Kuo-yu (Lisa) Wang Department of Social Welfare, College of Social Science, National Chung Cheng University, Chia-yi, Taiwan

Bernie Warren Faculty of Arts, Humanities and Social Sciences, Drama in Education and Community, School of Dramatic Art, University of Windsor, Windsor, ON, Canada

Karen Weigle University of New Hampshire, Durham, NH, USA

The Center for START Services, Institute on Disability/UCED, Concord, NH, USA

Isaiah Wexler Division of Pediatrics, Hadassah Hebrew University Medical Center, Jerusalem, Israel

Christine Wilkins New York University, Langone Medical Center, New York, NY, USA

Joanne Wilkinson Geriatric Education and Research, Fairview Hospital/ Cleveland Clinic Family Medicine Residency Program, Fairview Hospital, Cleveland, OH, USA

Meredith Wilkinson Perth, WA, Australia

Ashley Williams New Heights Behavioral Health, Colorado Springs, CO, USA

C. Ruth Wilson Department of Family Medicine, Queen's University, Kingston, ON, Canada

Suzanne Wilson Kent and Medway NHS and Social Care Partnership Trust, Canterbury, UK

Sarah Winter Division of General Pediatrics, Department of Pediatrics, University of Utah School of Medicine, Salt Lake City, UT, USA

Mark L. Wolraich University of Oklahoma Health Sciences Center, OU Child Study Center, Oklahoma City, OK, USA

David Wood Department of Pediatrics, ETSU College of Medicine, Johnson City, TN, USA

Anne Zajicek Obstetric and Pediatric Pharmacology and Therapeutics Branch, The Eunice Kennedy Shriver National Institute of Child Health and Human Development, NIH, Bethesda, MD, USA

Lindsey J. Zemanek Research and Training Center on Community Living, University of Minnesota, Minneapolis, MN, USA

Introduction

Although human beings share much about life with other life forms on the planet and live in a symbiosis with the flora and fauna, they have some unique traits. The most notable of these traits is the power and complexity of thought, the ability to communicate with others in complex ways to reflect the thought processes, the ability to adapt to dramatic changes in the environment, the ability to organize circumstances to meet changing needs and demands on resources, and the ability to support and nurture the most vulnerable of its incredibly diverse set of individuals. From this context comes the sentiment that the greatness of a society is measured by how it accommodates and takes care of its most vulnerable citizens.

Diversity is another of humankind's unique characteristics and is a significant part of its secret of success compared to other life forms. The strength and success of this diversity operates at two different and intersecting levels.

On one level is the diversity of abilities, talents and interests among individuals that, in the context of societies great or small, are required to manage the multiple needs of the society in which they live. The second area of human diversity to consider is the wide variation in levels of skill and ability ranging from complete independence for some, while others may have difficulty even taking care of their own basic needs. People who face these latter challenges fall into one of three broad categories. The first are newborn infants and young and developing children who have not yet achieved a level of personal independence and competence to deal with the challenges of life, but will earn and achieve independence and success over time. The second group is comprised of individuals who have significant limitations in one or more physical, mental or social functions that require varying degrees of assistance in order to be able to survive and function successfully beyond the childhood years. And, the third group consists of people who have succumbed to functional limitations as a result of chronic medical conditions or are at the extreme of old age where infirmity that can be physical or mental or both, require constant ongoing care for all their physical, emotional and social needs.

This book focuses on the second group of vulnerable citizens – those who we characterize as having intellectual and developmental disabilities (IDD). This group of individuals also represents a diverse and heterogeneous population who differ from each other in level of ability, nature of disability and need for assistance and support in order to achieve full potential. As no one

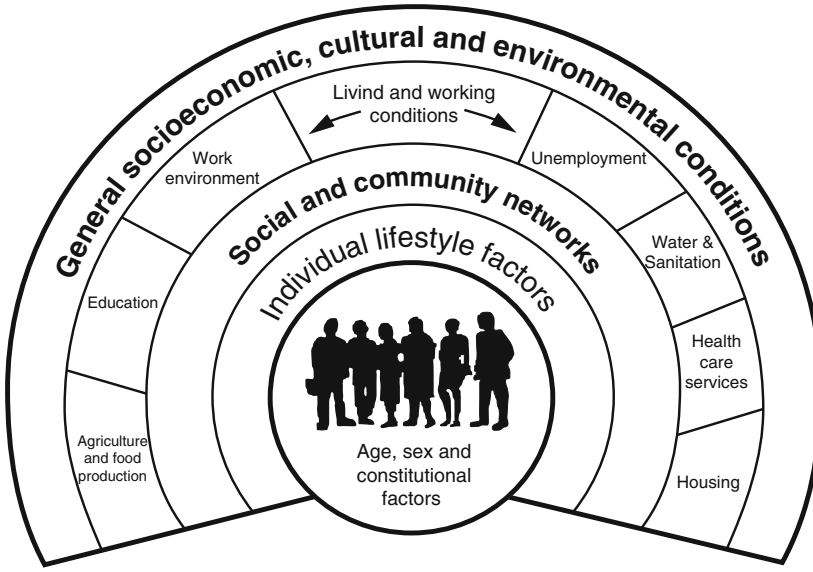

Fig. 1 Social context

person exists in isolation, we are all part of a group – a family, a community, a society – and we are all interdependent. The only difference between us is in the level of support we need to function to our full potential. The levels of support can be seen in Fig. 1.

My Personal Journey

During my pediatric training in Johannesburg, South Africa in the early 1970s, I was positively drawn toward the advances in care of the high-risk newborn infant. The potential of the newborn infant had always fascinated me, and we were seeing how these vulnerable infants, some of them very small and fragile, were being saved and going home with their parents to lead healthy and fulfilling lives. At that time, I discovered the new text on care of the high-risk newborn infant by Marshall Klaus and Avroy Fanaroff [1]. The book fascinated me, because of the new information about the subject, but even more so, by the style of the book. It provided the information, but also invited comments by other clinicians and researchers. This interactive style was novel and convinced me that I wanted to work with these people and, furthermore, it inspired the format of our own texts. Fortunately, I was accepted into the neonatology fellowship program at Rainbow Babies and Children's Hospital and Case Western Reserve University in Cleveland, Ohio and started in July of 1976. The atmosphere was stimulating and exciting with the novel practices and groundbreaking research that was taking place (see chapter "Health Care Transition" for a snapshot of the times).

During the course of my first year as a fellow, I became more interested in the neurological and psychological aspects of neonatology. Marshall Klaus and John Kennell [2] pioneered the concept of maternal-infant bonding and, through their research, demonstrated clear benefits. The practice at that time was to remove the infant form the mother immediately after birth, ostensibly to allow the mother to rest; to wash and swaddle the baby and to feed 'sugar water' as the first feed and diluted cow's milk thereafter, because at the time breast feeding was not in vogue; and, to bring the baby to the mother to feed every 4 h on the clock, because it was important to establish a routine. Klaus and Kennell revolutionized the practice by insisting on the baby remaining with the mother and having 'skin to skin' contact immediately after birth (where feasible). They also recommended breast feeding immediately and promoted the practice of breast feeding and of feeding on demand. This revolutionary practice resulted in major changes in the recognition of the importance of parents, especially early in life, and to breast feeding and breast milk, which have been found to have beneficial effects beyond nutritional. In addition, at that time, the advent of the CT scan enabled the identification of intraventricular hemorrhages and other insults to the developing brain that previously would only have been found at autopsy. My personal interest then became channeled to the neurodevelopmental outcome of the central nervous system (CNS) insults in the premature infants.

At this point, I left the neonatal fellowship and entered a fellowship in what was then called "Care of the handicapped child", an interdisciplinary program directed by Dr Robert Bilenker, providing comprehensive medical and supportive care to children with a variety of intellectual and developmental disabilities (IDD), including cerebral palsy, spina bifida, craniofacial anomalies, and other genetic conditions. After my fellowship, I joined the faculty and, as part of my responsibilities, I was assigned the position of medical director for a small residential facility for people with IDD. It was while I was in these roles that Allen Crocker recruited me to join him at the Developmental Evaluation Clinic (DEC), one of the Maternal and Child Health-funded interdisciplinary training programs at Boston Children's Hospital. Part of my responsibility there was as Director of Medical Education at the Wrentham State School in Massachusetts, where I started in 1980.

When I had completed my pediatric training at the end of 1975 and waiting to leave for the United States to take up my neonatal fellowship position, in July 1976, I did an elective in neurology with Dr David Saffer, which was the basis for my interest in the insults to the neonatal brain and their consequences. In addition, during my elective in neurology I was exposed to a school for children with cerebral palsy and had the opportunity to work in an interdisciplinary team for the first time. Both of these experiences were formative and prepared me well for my time in Allen Crocker's DEC. In addition, I realized that my interest in IDD had its origins in my childhood—I have two cousins with IDD, and grew up with them in my family. I recalled that my uncle, their father, wanted to take them to the USA for treatment, because there was not much available in South Africa, but unfortunately, maybe because of their IDD, he was not able to obtain a visa. My male cousin worked in his father's store, but my female cousin, who had CP,

stayed at home. They lived with their mother after their father died and when she was not able to care for them any longer, they went to live in a residential facility. My male cousin sadly died before his 80th birthday of acute hepatitis, which he contacted from a nurse who cared for him and who had also died of hepatitis. Up until this time there was no routine hepatitis vaccine in this facility, which was remedied, when I met with them. My female cousin died in April 2014 from a volvulus requiring surgical resection of a loop of necrotic bowel – she died 3 days after the surgery. They were both well cared for by their sister who visited at least on a weekly basis and I would always visit when I returned to South Africa to visit family.

I would like to dedicate this book to my family: my parents who provided the home, moral orientation and encouragement to pursue higher education; my cousins who unknowingly guided my career path; my wife Barbara who has always been there to provide me support and creative inspiration; my children, who have kept me young and have introduced me to new thoughts, ideas and visions of life beyond my narrow world; and their children who bring such joy and hope for the future: Justine, Robin, Felix and Reyn; Mandy, Tiran, Mikayla, Matan and Anik; Laila and Xandy – you are my inspiration. I would also like to recognize my extended family, my friends, my colleagues – past and present, and all the families who have entrusted their lives to me and have taught me so much. I only hope that I have given as much as I have been enriched. My message is to continue to pursue your dreams and do good deeds.

Background to the 3rd Edition

The first edition of this book was conceived and published in the late 1980s, with deinstitutionalization in full flourish. Lawsuits brought against states for the neglect and inhumane treatment of its citizens with IDD resulted in a variety of consent decrees to close institutions that, in some cases, dated to the mid-nineteenth century (see chapter "Family Centered Care in a Health Care Setting" on history). As a result of one such decree, the State of Massachusetts contracted with the Boston Children's Hospital (BCH) and Harvard Medical School (HMS) in 1976 to provide 'Health and habilitative services' to the Wrentham State School (WSS). Allen Crocker, the director of that contract, set up a system of primary care provided by physicians and mid-level practitioners employed by the BCH and HMS, and specialty services provided by a variety of specialty physicians within the HMS network, which included the Brigham and Women's Hospital. Dr. Crocker's vision of the services did not rest merely on the provision of medical care, but also on the provision of support services that included psychologists, physical therapists, occupational therapists, speech therapists, audiologists, nutritionists, social workers, educators, and other service providers as needed. The goal was to provide quality healthcare to the residents at the WSS and to facilitate their transfer into safe and secure community residences that would allow them to live in the community and have access to good healthcare and the other services needed to lead fulfilling lives. His vision included the education of health providers in the care of individuals with IDD and, to that end,

he recruited me to become the Director of Medical Education at the WSS in 1980. It was within this context that the accumulated knowledge gained by the physicians providing care at the WSS was realized and captured and coded into the book "Developmental disabilities: Delivery of medical care for children and adults" published in 1989 [3]. Although there had been other books on the subjects of developmental disabilities and intellectual disability, including attention to medical care, this was the first text that offered a lifespan approach to medical care.

The subtext to the book began in the 1950s, with awareness of human rights and the revelations of the abhorrent and inhumane care for the individuals within state institutions in the United States. These revelations came by a variety of means, e.g. the book "Christmas in Purgatory" [4] by Burton Blatt and Fred Kaplan and exposés on television (see chapter "Family Centered Care in a Health Care Setting"). These revelations resulted in the call for deinstitutionalization and closure of these facilities. The history of these institutions began in the mid- to late nineteenth and early twentieth centuries, with a real interest in the education of children modeled on European schools (see chapter on Denmark). Unfortunately, as history shows, these institutions became warehouses for children and adults with IDD, due in part to limited understanding and skills to provide this education and a loss of national interest with decreasing funding (see chapter "Family Centered Care in a Health Care Setting"). Several chapters of this book discuss the eugenics movement on which this social policy and practice was based. The perceived villains in this story were physicians and other healthcare providers, because the institutions were administered by the medical profession and based on a hospital system with nurses as the day-to-day providers of care, and the residents of the facilities were called patients. The despicable conditions in these institutions caused a sense of horror at the abuse of fellow human beings in the second half of the twentieth century after the world had seen the horrors of the Holocaust and had formulated the United Nations Declaration of Human Rights [5]. The reflex was to blame the medical profession. The term 'medical model' became laden with extreme negative connotation and, by association, anything medical was viewed with suspicion and disdain. Obviously, this was desperately unfortunate because good health, as we know, is critical to physical, emotional and social well-being. However, the new paradigm that was adopted at the time was the 'developmental model', which was a reflection, as much as anything else, of society's rejection of the medical model. The good news is that, over the course of time, the collective memory of the institutional era has faded into history as has the negative connotation of the 'medical model'.

It was into this environment that the 1st edition of this book was published, re-legitimizing the medical profession in caring, in a meaningful way, for people with IDD. There is an irony in the story of the book. The original publishers, Lea and Febiger, were taken over by another publishing company who immediately destroyed those books that were not best sellers. By the time this was realized, only 15 books remained and were salvaged, but, because of the unique elements of the book 'bootleg' copies were made and sold over the internet. The 2nd edition of the book was published in 2006 [6], and built substantially on the progress and knowledge gained over the intervening years.

In the late 1980s and early 1990s, there was a burgeoning of interest in the healthcare of individuals with IDD. There were three major factors in this process.

The first and primary mover was the establishment of the interdisciplinary training programs in the evaluation of children and adults with IDD and the 'Mental Retardation Research Centers' that were established at universities across the country as a result of the reports of the Presidents' Panel on Mental Retardation initiated by President John F Kennedy in 1961. These programs were funded by the Maternal and Child Health Bureau of the US Department of Health and Human Services. The other outcome of the Kennedy initiative was the establishment of the National Institute of Child Health and Development in 1962, which provided a center for research and further legitimacy to the field of IDD. These programs provided opportunities for pediatricians to explore the world of IDD from an interdisciplinary perspective and the other disciplines in the team were able to get a better perspective on the healthcare needs of the individuals with IDD. This foundation became one of the major factors in the formulation of the field of developmental pediatrics.

The second track in this process came from advances in pediatric care from care of the high risk newborn infant and the consequences of prematurity and other neonatal insults; the emergence of the field of genetics with the recognition of medical and neurodevelopmental characteristics as the children grew; the establishment of specialty clinics for various conditions that required long-term management, more often than not by an interdisciplinary team, such as for children with cerebral palsy of children with Down Syndrome; and, the recognition within the world of pediatrics of the "New morbidity", first noted in the early 1980s [7, 8]. This ultimately led to a new orientation in the practice of pediatrics, from the management of acute illnesses, generally of an infectious nature, to the development, behavior, learning and social factors that affected the health, growth and development of children into healthy productive and successful adults. The next level of consideration from the pediatric world came with the recognition of chronic conditions in children and the emergence of the term "Children with special healthcare needs" [9]. This gave further impetus to healthcare providers to recognize and relate to children with IDD, who clearly fell into this category.

The third track emerged simultaneously in many parts of the world, notably in Holland, Australia and Britain and the establishment of international societies involved in the exploration of the needs of people with IDD, and the sharing of research, ideas and practices around the world. This international surge in interest and involvement with IDD has been very heartening as there has been a proliferation of publications reflecting changes in practice from all parts of the world.

This progress made during the past decade and the obligation to update and document the advances and expand the audience with an international set of perspectives prompted the publication of this, the 3rd edition of this text on medical care for children and adults with IDD. The sad passing of Allen Crocker (1925–2011) meant the loss of a distinctive voice and vision, but his

spirit lives on and we have retained the theme and style of our previous editions. I had the good fortune of finding Joav Merrick as a new partner in the process, who has helped shape the international focus to this 3rd edition and also with help from Donald Greydanus and Dilip Patel who helped with the recruitment of quality authors and David Ervin who assisted admirably with the daunting challenges of editing as well as many others who reviewed chapters and provided vignettes.

This edition of the book captures an unprecedented range of international perspectives, due to the new partnership and international approach by Joav Merrick, that look at a more holistic approach to medical care. Importantly, the book uses the more inclusive terminology of 'intellectual and developmental disabilities', rather than 'developmental disabilities', and refers to lifespan instead of children and adults, and to health and healthcare instead of 'medical care' to offer a conceptually broader perspective in keeping with the WHO definition of physical, emotional and social well-being [10].

This book was conceptualized and designed to provide clinicians, professionals, academics, health administrators, policy makers and families a perspective of the levels of need for people with IDD, the necessary resources to meet the need, and to appreciate the ultimate benefit to all society at a personal as well as at a systems level with a global scope.

I. Leslie Rubin
lrubi01@emory.edu

President, Innovative Solutions
for Disadvantage and Disability
Atlanta, GA, USA
Associate Professor, Department of Pediatrics
Morehouse School of Medicine
Atlanta, GA, USA
Co-director, Southeast Pediatric Environmental
Health Specialty Unit
Emory University
Atlanta, GA, USA
Medical Director, Developmental Pediatrics
Specialists
Atlanta, GA, USA

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Part II

Systems of Delivery of Health Care

Section 1

Introduction

Introduction to Intellectual and Developmental Disabilities

1

Dilip R. Patel, Donald E. Greydanus, Joav Merrick, and I. Leslie Rubin

Abstract

Intellectual disability (ID) is the term used to describe a condition defined by limits in cognitive and adaptive abilities that affect function and initially manifest before 18 years of age. This term supplanted the earlier term 'mental retardation' within the past two decades. The term developmental disability (DD) was coined de novo in the 1970s when the Developmental Disabilities Act of the US Congress was passed. While an ID is determined by formal psychometric testing to assess the intelligence quotient and adaptive functioning, the term DD is more generic and may include elements of physical limitations in addition to the ID. Both terms are often used interchangeably and have been blended into the term intellectual and developmental disabilities (IDD) to be inclusive for or all individuals who have limitations in cognitive as well as physical functions that are: based on central nervous system dysfunction, manifest in the childhood years, and have lifelong implications. Our goal as members of society is to support and enhance the function of children and adults with IDD and their families and to assure optimal physical, emotional and social well-being in order for them to lead fulfilling lives.

D.R. Patel, M.D., MBA (✉)
D.E. Greydanus, M.D., DrHC (Athens)
Department of Pediatric and Adolescent Medicine, Western Michigan University Homer Stryker MD School of Medicine, 1000 Oakland Drive, D48G, Kalamazoo, MI 49008-1284, USA
e-mail: dilip.patel@med.wmich.edu; greydanus@med.wmich.edu

J. Merrick, M.D., MMedSci, DMSc
Division for Intellectual and Developmental Disabilities, Ministry of Social Affairs and Social Services, POBox 1260, IL-91012 Jerusalem, Israel
e-mail: jmerrick@zahav.net.il

I.L. Rubin, M.D.
President, Innovative Solutions for Disadvantage and Disability, Atlanta, GA, USA

Associate Professor, Department of Pediatrics, Morehouse School of Medicine, Atlanta, GA, USA

Co-director, Southeast Pediatric Environmental Health Specialty Unit, Emory University, Atlanta, GA, USA

Medical Director, Developmental Pediatrics Specialists, 750 Hammond Drive, Building 1, Suite 100, Atlanta, GA, USA
e-mail: lrubi01@emory.edu

I.L. Rubin et al. (eds.), *Health Care for People with Intellectual and Developmental Disabilities across the Lifespan*, DOI 10.1007/978-3-319-18096-0_1

Introduction

The term intellectual and developmental disability (IDD) is internationally accepted to describe limitations in cognitive and adaptive functioning. The evolution of the terminology from earlier diagnostic labels with negative connotations is a reflection of a better understanding of the concept of cognition and cognitive deficits within the scientific and socio-cultural contexts and, more importantly, the constant striving to provide this group of individuals with the respect and dignity they rightly deserve. Although IDD is initially identified in infancy and early childhood years, it has life-long implications for growth and development, education, independence, health care, employment, and community living.

Definition

According to the American Association on Intellectual and Developmental Disabilities (AAIDD), IDD "is a disability characterized by significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills" [1]. The assessment of intellectual functioning and adaptive behavior must take into consideration the expectations based on individual's age and culture as well as the influence on cognitive assessment of sensory, motor, communication, or behavioral factors, which should be taken into consideration in the administration of assessment instruments, and interpretation of the results of the tests.

In the United States, a widely used definition is taken from the Individuals with Disabilities Education Act, which defines IDD as "significantly sub-average general intellectual functioning, existing concurrently with deficits in adaptive behavior and manifested during the developmental period that adversely affects a child's educational performance."

According to the Diagnostic and Statistical Manual of Mental Disorders [2], IDD is defined as an intelligence quotient (IQ) of approximately 70 or below on an individually administered standardized test of intelligence, concurrent with deficits in adaptive functioning in two of the following areas: communication, self-care, home living, social or interpersonal skills, use of community resources, self-direction, functional academic skills, work, leisure, health, and safety. All definitions stipulate that the onset of disability must occur before the age of 18 years.

It is generally agreed that, although not perfect, appropriately measured IQ provides the best estimate of intellectual functioning. Based on the mean value for IQ of 100, the upper limit of 70 represents the value that is two standard deviations below the mean. Because there is a five point standard error of measurement, it is argued that a range of 70–75 should be considered as the upper limit of IQ as the cut off value for intellectual disability. Theoretically, therefore, an individual with an IQ score of 75 with significant adaptive deficits will be considered to have an ID, whereas an individual with no adaptive disability and an IQ score of 70 or even 65 may not be considered to have an ID.

The severity of IDD is further categorized based on intellectual functioning, adaptive functioning, and intensity of supports needed [1] (see Table 1.1). When the level of intellectual disability cannot be reliably assessed, but there is a high level of confidence based on clinical judgment, a diagnosis of IDD is made without necessarily specifying the severity. Ultimately, however, the designation is a practical one and relates to ability of the individual to function independently within a relatively typical context in a family and in a community.

Epidemiology

The reported prevalence of IDD reflects consideration of the definition used, method of ascertainment of the data, and the characteristics of the population studied. Based on the typical bell-shaped distribution of intelligence in the general population, then 2 standard deviations below the mean, which is approximately 2.5 % of the population, is expected to have IDD. Most epidemiological studies consider those with an IQ score of

Table 1.1 Classification of level of intellectual disability [2]

Severity level	Percent of individuals who have intellectual disability	Intelligence quotient range	Intensity of supports needed in daily living activities such as school, work, or home
Mild	85	From 50–55 to 70	Intermittent: Support on as needed basis, episodic or short-term
Moderate	10	From 35–49 to 50–55	Limited: Consistent over time, but time limited
Severe	4	From 20–25 to 35–40	Extensive: Regular, consistent, lifetime support. Regular support in at least one aspect such as school, work or home
Profound	1	Less than 20–25	Pervasive: High intensity, across all environments, lifetime, and potentially life-sustaining

Based on American Psychiatric Association. DSM-IV-TR, 2000; American Association of Intellectual and Developmental Disabilities. Mental Retardation, 2002

50 or less as having severe IDD, and those above that as having mild IDD. Using these designations, 85 % of individuals with ID will have mild levels of disability, 10 % will have moderate ID and the remainder will have severe or profound levels of ID. The prevalence of severe IDD has remained constant over several decades at 0.3–0.5 % of the general population in the United States. Based on the United States National Center for Health Statistics 1997–2003 National Health Interview Survey, the prevalence of IDD among children ages 5–17 years is estimated to be 7.5 per 1000 [3].

Intellectual disability is reported to be twice as common in males compared to females. The recurrence risk of IDD in families with one previous child with severe IDD is reported to be between 3 % and 9 % [3].

A specific etiology can only be identified in less than half of individuals who have mild degrees of ID, while an underlying biological or neurological etiology can be identified in more than two-thirds of individuals who have severe IDD [3]. Etiological factors are predominantly prenatal in origin and include chromosomal anomalies, genetic syndromes, congenital brain anomalies, congenital infections, inborn errors of metabolism, neurodegenerative disorders. Perinatal factors include prematurity or birth injury, while postnatal etiologies include CNS infections such as meningitis or encephalitis, brain injury from accidental and non-accidental causes, including child abuse like "shaken baby" syndrome and environmental factors such as lead toxicity. However, by far the most common potentially preventable causes are directly or indirectly related to socioeconomic factors which effectively 'shift the population distribution curve' (see chapter "The Sphingolipidoses").

Clinical Features

At this point it is appropriate to use the term to IDD, because the discussion becomes inclusive of all conditions rather than focusing exclusively on the cognitive measures. Children who have IDD can present with a wide range of initial clinical symptoms and signs depending up on the underlying cause and severity of the disability [4–9]. Children who have delays in motor milestones will present early while children with learning disabilities or behavioral symptoms and are identified relatively later. Common presentations of IDD by age are summarized in Table 1.2. The age at which IDD is recognized also depends on its severity (see Table 1.3).

Other mental disorders (see Table 1.4) are 3–4 times more common in children with IDD [10]. Some children may present with behavioral symptoms which may dominate the clinical picture. The term dual diagnosis is used in the situation of a co-morbid mental/behavioral disorder with IDD.

Table 1.2 Common presentations of IDD[a] by age

Age	Area of concern
Newborn	Dysmorphic syndromes, congenital CNS anomalies or organ system dysfunction that affect vital functions such as feeding
Early infancy (2–4 months)	Limited interaction with mother or the environment Concern about vision and hearing impairments
Later infancy (6–18 months)	Developmental motor delay Unusual patterns of behavior
Toddlers (2–3 years)	Language delays or difficulties Unusual patterns of interaction, particularly with parents, siblings or peers Unusual patterns of behavior
Pre-school (3–5 years)	Language difficulties or delays Delays in fine motor skills: cutting, coloring, drawing Behavioral challenges, including play and social interactions
School age (older than 5 years)	Academic difficulties Behavior challenges such as difficulty with attention, as well as emotional manifestations such as anxiety or mood disorders

Used with permission from Shapiro and Batshaw [7], 191–7, Table 38-4, p. 193

[a]The term, mental retardation (MR), from source, is replaced with intellectual and developmental disability (IDD)

Table 1.3 Key elements of history

Details of presenting symptoms
Onset, duration, progression, severity of symptoms
Current level of development and functioning as reported by parents or caregivers
Family history
Unexplained fetal, infant or childhood deaths
Parental and sibling health
Medical conditions in family members: congenital, genetic, neurological, psychiatric, learning disorders, intellectual disability, speech and language disorders
Personal/social history
Parent occupation, socioeconomic status, level of education
Primary caregiver, living situation, school functioning
Prenatal
Family history
Mother's and father's age at birth of the child
Previous pregnancies: number, term, preterm, abortions, living
Nature of prenatal care
Maternal medical and obstetric complications
Use of medications, drugs of abuse, alcohol, tobacco, radiation exposure
Pre-natal maternal infections
Maternal weigh gain
Multiple gestations
Fetal activity
Perinatal
Length of gestation
Hospital or home delivery details
Intrapartum monitoring, use of analgesia or anesthesia (epidural)
Maternal history for fever, toxemia, abnormal bleeding, abnormalities of placenta
Labor: spontaneous delivery, induced, vaginal, forceps, cesarean section
Complications such as polyhydramnios, oligohydraminos, prolonged rupture of membranes breech presentation or prolapse cord
Meconium or foul-smelling amniotic fluid
Neonatal
Apgar scores
Need for resuscitation
Birth weight, length, head circumference
Small or large of gestational age
Congenital anomalies
Respiratory distress, assisted ventilation, apnea, seizures, sepsis, jaundice
Neurological status
Brain imaging, laboratory testing
Feeding problems Duration of nursery stay
Developmental
History of developmental milestones
Time and nature of initial parental concerns about development
Any previous developmental evaluations
Specific developmental diagnosis if any and at what age
Any current services or therapies, early intervention or other special health services
Social history
Extracurricular activities, family adjustment, school adjustment
Medical/surgical
Major illnesses or surgeries
Injuries and hospitalizations
Procedures or investigations
Use of medications
Review of systems
Guided by presenting symptoms

Table 1.4 Selected standardized instruments

Measures of cognitive abilities	
Instrument	**Age range**
Bayley Scales of Infant Development III	1–42 months
Wechsler Pre-School and Primary Scale of Intelligence	2 years 6 months to 7 years 3 months
McCarthy Scales of Children' Abilities	2 years 6 months to 8 years 6 months
Stanford-Binet Intelligence Scale (5th edition)	2–85 years
Wechsler Intelligence Scale for Children (WISC-IV)	6–12 years
Leiter International Performance Scale-Revised (Leiter-R)	2–21 years
Measures of adaptive abilities	
Instrument	**Age range**
Vineland Adaptive Behavior Scale II (VBAS II)	Birth to 19 years
Adaptive Behavior Scales II (ABAS II)	Birth to 89 years
Scales of Independent Behavior-Revised (SIB-R)	Birth to 80 years
AAMR Adaptive Behavior Scales (ABS)	3–21 years

Diagnosis

For individuals with IDD there are multiple associated developmental domains and often other co-occurring conditions, therefore an interdisciplinary approach is strongly indicated. Diagnosis is made based on etiological considerations, dominant presenting problems, severity of the condition and co-occurring disorders. It is critical to obtain a complete and comprehensive history (see Table 1.5) followed by a complete and detailed general physical examination, with a focus on physical features and neurological examination. A work up should obviously include compete audiological and vision evaluation in all children [4–9]. Technically, a diagnosis of IDD requires individualized cognitive and adaptive testing by qualified examiners using standardized instruments (see Table 1.6). Standardized testing should be age appropriate, take into account develop mental age of the child, and the cultural background which can significantly influence the child's ability to perform in the test; it should be remembered that whatever test is used for this purpose should be specific to a language and culture, for example, for English speaking children in the USA or in the UK, or for French speaking children in France. Care must be taken, therefore, to be sensitive to the background, language, culture, education and life experiences of the child (or adult) who is being evaluated. Appropriate accommodations should also be made for any motor, behavioral, sensory disorders or other complicating factors.

While it is important to try to establish the etiology for the IDD, this may not always be possible. Etiological diagnosis should be pursued if there are specific developmental, physical or med-

Table 1.5 Factors that may guide decision to pursue etiological diagnosis

Family history
If there is a family history of medical, neurological, developmental, learning, or behavioral problems
Severity of intellectual disability
Biologic cause can be found in 75 % of individuals with severe intellectual disability
Presence or absence of disease specific symptoms and signs
Disease specific features may indicate which tests to order
Parental decision as to future pregnancy
If more children are planned, a pre-natal diagnosis and early appropriate intervention may be planned
Parental desire to know the cause of intellectual disability
Varies. Some may want to know so that specific disease may be treated if treatment is available. Other may want to focus on services

Table 1.6 Reasons offered in support of pursuing an etiological diagnosis

Associated complications can be anticipated
Specific cause may be treatable
Aid in the development of prevention strategies
Intervention can be planned for anticipated behavioral symptoms
Genetic counseling can be provided
Helps in long-term life planning
Research is facilitated

ical characteristics and particularly, if there are unusual physical or medical characteristics and critically if there is any loss of function or failure to grow or develop which could indicate an inborn error of metabolism or neurodegenerative disorder. Factors that might guide the decision to pursue etiological diagnosis are summarized in Table 1.5 and some reasons offered by those who favor such an approach are summarized in Table 1.6.

Approach to Management

Children with IDD are best supported through an interdisciplinary team approach in the setting of a medical home [11]. Early identification and early intervention, with appropriate therapies and family support, are critical to establishing the framework for long term services and support, and for promoting optimal development for the child as well as providing families with an understanding of the therapeutic needs of their child. Such an approach further sets the stage for families' awareness of the social network that is destined to be part of their lives for the foreseeable future. The physician should provide general medical care according to established guidelines. Specific health maintenance guidelines for children are published by the American Academy of Pediatrics for several conditions e.g., Down Syndrome, and can be accessed at www.aap.org. It is critically important that the clinician have a good working knowledge of medical and community resources that may be required and should have ongoing communication to facilitate and coordinate the child and family's needs in the spirit of the Medical Home (see chapter on Medical Home).

As the child grows, so too do his or her needs change from the early intervention services to school-based services, and then to transition to the needs of a young adult and through the adult years on to old age and geriatric services. Advances in medical care and in social services have played a part in the increased lifespan of individuals with IDD resulting in the need to support the families as well as the individuals with IDD. It is important to remember at all times, that the individual with IDD lives in the context of a family, of a community and of society at large.

Public Services

In the United States, several Federal and State laws provide the framework and funding for intervention programs and educational services for children with IDD (see section "Reaching the Unserved and Underserved: Medical Care in Rural and Urban Settings" of chapter "The Rights of Individuals with Disability to Parenthood"). The mainstay of support for infants from birth three years of age and their families is early intervention services provided by local community agencies through the development and implementation of the Individualized Family Service Plan. For children and adolescents between the ages 3–22 years the main focus is on meeting the child's educational needs, the Individualized Education Plan (IEP) which is developed and implemented by the student's school district. Between 14 and 16 years of age an Individualized Transition Plan (ITP) is developed that addresses the student's transition to adult services, vocational preparation, and independent living. After completion of high school, the individual is supported by the Individualized Habilitation Plan (IHP) that provides support services for adults. The intensity of support services needed depends up on the severity of the IDD (see Table 1.1). The adult outcomes and functioning of individuals with IDD are summarized in Table 1.7 [12].

Transition to Adult Services

Puberty and adolescence bring hormonal, behavioral and social changes that announce imminent adulthood. Almost all the laws described above are specifically for children, particularly early intervention programs and special education services, and children also have the benefit of pediatricians and developmental pediatricians who have known them since infancy, as well as many specialty pediatric programs. Unfortunately, there are limited services for adults with IDD,

Table 1.7 IDD and adult reference age functioning

Level	Mental age as adult	Adult adaptation
Mild	9–11 years	Reads at 4th–5th grade level; simple multiplications/ divisions; writes simple letters, lists; completes job application; basic independent job skills (arrive on time, stay at task, interact with co-workers); uses public transportation; may qualify for recipes
Moderate	6–8 years	Sight-word reading; copies information e.g., address from card to job application; matches written number to number of items; recognizes time on clock; communicates; some independence in self-care; housekeeping with supervision or cue cards; meal preparation, can follow picture recipe cards; job skills learned with much repetition; uses public transportation with some supervision
Severe	3–5 years	Needs continuous support and supervision; may communicate wants and needs, sometimes with augmentative communication techniques
Profound	Less than 3 years	Limitations of self-care, continence, communication, and mobility; may need custodial or nursing care

Used with permission from Shapiro and Batshaw [7], 191–7, Table 38-6, p. 197

and these are heavily dependent on state and local services, many of which are privately developed by family members and often funded by charitable organizations and businesses. It becomes critically important to begin to prepare the young teenager for a meaningful and productive life after graduation from high school with anticipatory planning (see section "Transitioning Youth to Adult Health Care: A Person-Centered and Culturally Competent Approach" of chapter "Siblings of Children and Adults with Intellectual and Developmental Disability"). At this stage, questions emerge about post graduate education, vocational training, exploration of employment opportunities, the preparation for the options for independent living and the need for adult oriented health services. Often neglected is the important consideration for a social life. While in school a child wakes up every morning with a place to go where there are people and a schedule of activities in an active nurturing and social environment. After graduation, if there are no plans in place, there is nowhere to go in the morning and nothing to do all day, except watching TV and perhaps minor sporadic outings. This sedentary life can contribute to depression and obesity, so it is very important to begin to plan early and to develop the necessary skills and set up the infrastructure for relative independence as well as for a fulfilling and satisfying life.

Adult Life and Aging

Programs and services for adults are not as varied, fulfilling or plentiful as for children, but with available federal and state programs, creative local programs and with resourcefulness, individuals with IDD can go on to lead satisfying, and productive lives, each consistent with his or her own potential abilities.

Improvements in healthcare for adults with IDD has resulted in increases in lifespan over the last century, which are substantial and worthy of celebration. Guidelines for the management of adults with IDD are emerging with major contributions from The Netherlands and from Canada (see sections "Canada" and "Service Organization and Support for People with Intellectual and Developmental Disabilities in the Netherlands" in chapter "Reaching the Unserved and Underserved: Medical Care in Rural and Urban Settings"), and approaches in the management of older individuals with IDD have been developed with integration into generic geriatric services (see chapters on aging....).

Conclusions

IDD is a term used to describe a segment of a population who have limited intellectual abilities and other characteristics that begin in childhood and have a lifelong affect their ability to function independently in society. Over the past century significant knowledge and resources have developed to meet the needs of children and their families and, also for adults and the aging population which has resulted in an improvement in quality of life and in the lifespan of all individuals with IDD. It is therefore important for all clinicians involved to have an understanding of the etiology, presentation and characteristics of each individual as well as the services available to help that individual reach his or her full potential within the context of the family, the community and society. Although we have made substantial progress, there is still much to learn and develop to assure that each individual leads a fulfilling and satisfying life and assure that there is full integration and inclusion for all people with IDD into all aspects of society.

Acknowledgements This chapter is revised and adapted from Patel DR, Merrick J. Intellectual disability, In: Patel DR, Greydanus DE, Omar HA, Merrick J, eds. Neurodevelopmental disabilities. Clinical care for children and young adults. Dordrecht: Springer, 2011:161–71 (3).

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Section 2

Health

Health Is More than Medicine

2

Donald J. Lollar and Randall A. Phelps

Abstract

The World Health Organization definition of "health" has become all but a cliché. It is often used to highlight the need to address issues beyond the traditional medical model, often associated with deficits, disease, or disability. Most often the definition is all that is provided. The specifics of how a medical practitioner or a medical organization moves beyond medicine toward a focus on health are usually sketchy, at best. While health is certainly the outcome that medicine addresses, the emphasis is most often the reduction or elimination of deficits or deficiencies. This chapter will address the varied secondary conditions to which individuals with developmental disabilities are most vulnerable, and will identify the attitudes, approaches, and practices (the barriers) that undermine the health of individuals with developmental disabilities. We will balance this by identifying concepts, approaches, and practices that can encourage health. Health promotion is the process of enabling people to increase control over, and to improve, their health. This goal of helping individuals increase control over their health, with the requisite understanding and behaviors to improve their health is a critical one for individuals with developmental disabilities. Myers concluded that if individuals with developmental disabilities are to move toward health, there is a need for "greater professional humility to appreciate that people with both physical and intellectual impairments are able to experience and articulate their own satisfaction, pleasure, and joy". Medicine is a crucial component of health, but health is more than medicine.

D.J. Lollar, EdD (✉)
Department of Public Health and Preventive Medicine, School of Medicine

University Center for Excellence in Developmental Disabilities (UCEDD)

Institute on Development and Disability, Oregon Health and Science University,
707 SW Gaines Ave, Portland, OR 97239, USA
e-mail: lollar@ohsu.edu

R.A. Phelps, M.D., Ph.D.
Child Development and Rehabilitation Center, Institute on Development and Disability, Oregon Health and Science University, 901 East 18th Avenue, Eugene, OR 97403, USA
e-mail: phelpsr@ohsu.edu

I.L. Rubin et al. (eds.), *Health Care for People with Intellectual and Developmental Disabilities across the Lifespan*, DOI 10.1007/978-3-319-18096-0_2

Introduction

WHO definition of health: "Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" [1]. The World Health Organization definition of "health" has become all but a cliché. It is often used to highlight the need to address issues beyond the traditional medical model, often associated with deficits, disease, or disability. Most often the definition is all that is provided. The specifics of how a medical practitioner or a medical organization moves beyond medicine toward a co-emphasis on health are usually sketchy, at best. While health is certainly the outcome that medicine addresses, the emphasis is most often the reduction or elimination of deficits or deficiencies. "Health care" is the term used to connote what medical professionals do toward this end and covers diagnosis and intervention of medical conditions, with the best coverage including activities associated with "prevention" of medical conditions, but rarely the promotion of "physical, mental, and social well-being"; stated positively, health.

Medical practice has been improved specifically by including the prevention of secondary conditions associated with primary medical conditions as a component of practice. Even this addition, however, does not insure an emphasis on promoting health. If we are to address medicine, but allow it to be included in the broader notion of health, what concepts, approaches, and behaviors ought we to pursue? And can we assume that these components apply equally to individuals with developmental disabilities? For this chapter, we assume that (a) health is more important for this group than for the general population, and (b) the barriers to health are greater for this group.

We also assume that individuals with developmental disabilities will include individuals both with and without intellectual impairments. Boyle et al. [2] reported a developmental disabilities prevalence of 15 % among children aged 3–17 years, with autism, and attention deficit hyperactivity disorder increasing, while hearing loss decreased over a 12 year period. The Administration on Intellectual and Developmental Disabilities (AIDD) estimated that between 7 and 8 million Americans across the life span (3 % of the population) experience an intellectual disability [3]. Given increased vulnerability of this population, health promotion and prevention of secondary conditions are particularly crucial for the individual, their family, and the health system. This chapter will address several pivotal issues:

- We will define and outline secondary conditions to which this population is most vulnerable.
- We will identify the attitudes, approaches, and practices (the barriers) by which "health professionals" unwittingly undermine health of individuals with developmental disabilities.
- We will identify which concepts, approaches, and practices can encourage health beyond, but including, medicine.
- We will identify environmental factors within and outside medical offices and facilities that can undermine or facilitate the health of this population.

The term "secondary conditions" has evolved since the early 1990s [4–6]. Basically, it can be defined as "any preventable condition to which a person or family is more susceptible by virtue of experiencing a primary diagnosis associated with disability" [4]. The term refers to outcomes for which a person is at greater risk due to the presence of a primary disabling condition. That is, the primary diagnosis is a risk factor for the appearance of a secondary condition. Secondary refers to timing-when the conditions occur—and does not mean that the conditions are less serious. The term "conditions" is used to suggest that the varied outcomes are not exclusively in the medical or physical domain of function but can also include emotional, social, and environmental dimensions.

Several examples of secondary conditions for individuals with developmental disabilities may clarify the concept. Urinary tract infections and

pressure sores are secondary conditions often seen in individuals with spina bifida or spinal cord injury. That is, they are conditions for which the person is at greater risk because of the primary disabling condition. Social isolation and depression are conditions experienced by individuals with various developmental disabilities. Without wishing to stretch the concept too far, one can entertain that reduced access to health care or injuries to family caregivers can also be considered secondary conditions for clinical purposes. In clinical practice, secondary conditions often can be more severe and disruptive than the stabilized primary diagnosis and have implicitly adverse consequences. Much, if not most, clinical time is spent addressing the secondary condition(s), beyond the primary medical condition creating body dysfunction. One of the clinician's tasks is to work with individuals with developmental disabilities and their families to preventor reduce the impact of such secondary conditions on the person and family.

In daily appointments at clinics, little distinction might be made between primary symptoms and secondary conditions for the person with disabilities or his or her family. Diagnosis is diagnosis; treatment is treatment; intervention is intervention. The most relevant distinguishable clinical element of secondary conditions is that they are preventable. That is, although there is a greater risk for the occurrence of them, secondary conditions are not part of the primary manifestation(s) of a diagnosis. Depending on the clinician, evaluation and diagnosis of secondary conditions shows wide variations in the comprehensiveness. In addition, the less medical the secondary condition, the less attention may be given to assessment and interventions. This lack of comprehensive attention may be based on the assumption that the individual with developmental disabilities, with or without intellectual impairments, cannot adequately communicate concerns or problems—or that the information will not be accurate or relevant or helpful. Secondary conditions can take different forms. Crocker [7] developed a typology reflecting the range and complexity often found:

- Complication: An untoward occurrence, accidental but resulting from the primary condition (e.g., pressure sore in spina bifida)
- Contingency: An event involving another body system but ultimately deriving from the conditions of the primary condition (e.g., conductive hearing impairment associated with Down syndrome)
- Unexpected progression: A troubling extension of the potential continuing natural history of the primary condition (e.g., loss of ambulation in cerebral palsy)
- Comorbidity: Another parallel condition, deriving from the same background as that producing the first diagnosis (e.g., hydrocephalus and spina bifida).
- Other health concerns: Ill health from other origin but perhaps masked or confounded in some fashion by the primary condition (e.g., obesity in Down syndrome)
- Effects of aging: Liabilities or dysfunctions due to advancing years, often accelerated by a primary condition (e.g., overuse syndrome related to mobility problems)

To complement this typology, we could add social and emotional issues—those that emerge primarily because of the developmental disability experienced by the individual. As indicated earlier, secondary conditions should not be viewed only as medical conditions, but as any condition to which the individual is more vulnerable by virtue of their primary condition. This would include, for example, social isolation, identity issues, and emotional adjustment concerns.

In the field of developmental disabilities, the world of secondary conditions is a large and often complicated one. Varied therapeutic, educational, technological, environmental, and social interventions must be considered during clinical encounters with the individual and his or her family. As a matter of course, practitioners working with people with developmental disabilities usually are already aware of the breadth and complexity of secondary conditions and alternative interventions that are part and parcel of these interactions. Nonetheless, the skill and sensitivity of the

provider will be challenged beyond the medical issues to the health issues of the person and his or her family. Consider the following vignette:

Case 1: Elizabeth is an 18 year-old high school senior who is preparing to go off to college in the fall. She has cerebral palsy and a complex past medical history, including multiple surgeries, including soft tissue releases, two femoral osteotomies, and a spinal fusion. She has long-standing history of severe, debilitating migraines. Elizabeth is bright, at the top of her graduating class, and has already received a scholarship from a nearby liberal arts college. She has travelled internationally and is fluent in French. She is always well groomed and wears fashionable clothes. Elizabeth recognizes that many people see her in her wheelchair and draw immediate conclusions about her intellect; and that others encounter her intellect and cannot imagine the disabilities she has. Just as Elizabeth is preparing for the independence she anticipates in her college experience, her hip surgery begins to fail and she experiences unrelenting pain. On chronic pain medications, she struggles with sedation, gains weight, and develops severe bowel impactions. As Elizabeth makes the rounds of physicians in her senior year, her various specialists provide care and attention to her specific concerns, but do not address the secondary conditions now developing. None of her physicians ask about her weight gain or her bowel functions. None of her physicians encourage exercise or discuss nutrition. (Is depression identified? If so, is it just addressed with medication?)

Elizabeth's story may provide some insight into the care of young adults with disabilities. The great disappointment for Elizabeth and her family was the instability of her health at age 18 years. Most of what they had read suggested that cerebral palsy did not lead to additional health concerns. This very bright, engaging young woman's academic performance masked her problems so much that many teachers and peers could not imagine that someone so bright could have so many disabilities. Moreover, the increasing health problems that demanded attention drew her physicians away from efforts to integrate health care, that is, to address depression, weight, conditioning, and bowel functioning, as well as to address her hip problems and her headaches.

Areas of Disparity

"Health disparity", usually suggests a negative difference in the health status of people with a certain characteristic when compared to the general population. For people with developmental disabilities, health disparities can create the conditions for developing secondary conditions. That is, if people with developmental disabilities are less able to access health care, their vulnerability to myriad secondary conditions is increased [8]. Havercamp, Scandlin and Roth [9] reported results from the North Carolina Behavioral Risk Factor Surveillance System comparing adults with developmental disabilities with non-disabled adults. The data indicate numerous areas of disparity, beginning with the sedentary lifestyle of those with developmental disabilities; specifically, individuals in the developmental disability group were significantly more likely to have had no exercise in the previous month than those without disabilities. These individuals also were much more likely (seven times) to indicate poorer emotional support than adults without disabilities. In addition, this population had significantly poorer utilization of oral health care and the women with developmental disabilities reported having breast and cervical cancer screening much less often.

The National Core Indicators is a state-based survey specifically focusing on individuals receiving developmental disabilities services. The 2010–2011 NCI Annual Summary Report [10] indicated that while 75 % of adults in the survey had received a flu vaccination in the past year, only 39 % had ever had a pneumonia vaccine. Only 19 % of the respondents over 50 years had a colorectal screening in the past year. The report concluded that for almost all services, individuals with developmental disabilities living with par-

Table 2.1 Estimated prevalence of secondary conditions in adults with developmental disabilities

Secondary condition/problem	Estimated prevalence/1000
Physical fitness and conditioning	590
Communication	573
Mobility	509
Persistence or low frustration tolerance	500
Weight	479
Personal hygiene or appearance	470
Dental and oral hygiene	451
Fatigue	422
Depression	369
Sleep disturbance	316
Bowel dysfunction	288
Respiratory	178
Cardiovascular/circulatory	156
Osteoporosis	112

From Traci et al. [12]; adapted by permission

Table 2.2 Adolescent spina bifida secondary conditions rank order

1. Bladder incontinence	7. Recreational problems
2. Learning/memory	8. Self-esteem problems
3. Physical fitness	9. Fatigue
4. Mobility problems	10. Headaches
5. Initiation/motivation	11. Social isolation
6. Bowel incontinence	

Adapted from Lollar [13]

ents or relatives and those living independently were less likely to have received appropriate services than those individuals living in community-based housing and in institutional settings.

Emergency department (ED) use by working adults with disabilities provides a broader view of related to access and service needs. Rasch, Gulley, and Chan [11] pooled the Medical Expenditure Panel Survey Data from 2006 to 2008 and found that while 17 % of the US working age adults report some type of limitation, this group accounts for 40 % of ED visits. They concluded that even given that people with disabilities may experience more health problems, ED use could be reduced with better access to regular medical care, and attention to the complexity of individual's health profiles.

Traci, Seekins, Szalda-Petree, and Ravesloot [12] completed a study in Montana of the prevalence of secondary conditions among a group of 119 adults across a broad spectrum of living arrangements, from independent residences to residential care facilities. Communication difficulties were reported most frequently by the direct care providers who completed the survey, followed (in descending order of importance) by problems with physical fitness and conditioning, persistence or low frustration tolerance for task completion, weight, personal hygiene, dental and oral hygiene, fatigue, depression, mobility, and sleep disturbance. Traci et al. [12] concluded that these limitations all included significant behavioral or life style components; more medically oriented conditions, such as gastrointestinal dysfunction, bowel problems, or respiratory difficulties, were reported substantially less often. Looking closely at the list, one sees the correlation among several of the conditions—conditioning is related to weight, which is related to appearance, which is related to mobility, which is related to fatigue, which ultimately is related to sleep and depression. This relationship is, of course, just one of a number of cyclical groups that can be generated among the secondary conditions listed in Table 2.1. Although some of these conditions (e.g., depression, sleep disturbance) might have diagnostic codes, several do not (e.g., fitness, low frustration tolerance, personal hygiene). Thus, a clinician's inquiring about some of these conditions would not necessarily be a part of routine patient-clinician encounters.

Lollar [13] amended the Secondary Conditions Surveillance Instrument [14] to identify secondary conditions among a sample of adolescents with spina bifida. Table 2.2 provides the rank order of the most problematic secondary conditions for this sample. Incontinence of bladder (ranked first) and bowel (sixth) were the two medically associated secondary conditions, although the definitions for these two conditions included in the instrument clearly related to the preventable negative social aspects of in conti-

nence rather than just the body dysfunction. In addition to limitations in learning (second) and mobility (fourth), secondary problems of everyday living were prominent. Physical fitness (third), motivation (fifth), self-esteem (eighth), and fatigue (ninth) overlapped with the secondary conditions of the adults in the Montana sample. This exercise showed, as might be expected, that young people with spina bifida contend with the social aspects of bowel and bladder incontinence as well as with the general problems of everyday life. Also, cross-cutting issues related to fitness, motivation, mental health, and fatigue emerge.

Havercamp [15] completed a population-based survey in North Carolina of health needs of adults with developmental disabilities. Information was collected from the adults and their case managers. Physical fitness and obesity were the major problems that emerged. A high rate of mental health problems was found, and more than half of those in the representative state sample were being prescribed medication for mental health problems. It is possible that this may represent over-reliance of medication, both for treatment of mental health problems, and for misattribution of difficulties to mental health problems. Finally, the survey indicated that access to health care services was often difficult, with particular problems in oral health services and in reproductive services for women. The study concluded that lack of physical activity was a risk factor for chronic conditions, such as cardiac disease, and that there was an alarmingly elevated rate of emotional problems associated with inadequate support and high stress. Moreover, adults with developmental disabilities have high rates of tobacco and alcohol use, thus creating additional risk factors for stroke, lung cancer, and respiratory disease.

Data clearly indicates that secondary conditions, including problems with access to care, are a part of the life experience of individuals with developmental disabilities. Together, the aforementioned studies indicate that physical fitness, obesity, and emotional issues are frequent secondary conditions among these groups. Associated with these conditions are motivation, persistence or low frustration tolerance, poor communication, difficulty with personal hygiene, fatigue, mobility limitations, and sleep disturbance. Finally, obtaining oral health services and reproductive services is often difficult; however, services for emotional issues and associated medications seem to be rather well identified and readily available, contrary to anecdotal evidence.

In summary, the data is consistent with the Surgeon General's report [16]. The report included a list of under-recognized medical problems—including constipation and impaction, visual and auditory problems, recurrent ear infections, periodontal disease and infected teeth, osteoporosis, and neuropathies—to which individuals with intellectual disabilities are more vulnerable. This list, however, does not include the broader range of secondary conditions (emotional, familial, social, and environmental) encountered in clinical settings. The report, "Closing the gap: A national blueprint to improve the health of persons with mental retardation", concluded that individuals with cognitive impairments experience poorer health and have more problems "finding, getting to, and paying for appropriate health care."

Barriers to Diagnosis/Assessment/ and Health Promotion

To highlight the potential secondary conditions or associated health difficulties, consider the following cases:

Case 2: Diego is a 45 year-old man with intellectual disability, who lives in a group home. He is mildly obese and mildly hypertensive but has no other known health problems. He presents to his primary care physician (PCP) with lower abdominal pain and mild fever of several days duration. His provider collects a urine sample. On dip urinalysis, a large number of white blood cells and red blood cells are noted. Diego is started on empiric antibiotics, pending results of urine culture. Urine culture grows several organisms, consistent with it

being an inadequate specimen (not a "clean catch"), and Diego's care providers are instructed to have Diego complete the course of antibiotics. Diego's abdominal pain does not resolve; in fact, it worsens, and his fever persists, over the next few days. Another urinalysis is obtained, again showing white blood cells, consistent with infection, and another course of antibiotics is prescribed. Two days later, Diego is found lying in bed, incoherent. His fever is 104°, and he is taken to the ER. His blood pressure, which usually runs high, is now running low, and continuing to decline, even on IV fluids. Blood counts show elevated white cell count, with relatively high neutrophils, consistent with sepsis. With blood cultures pending, Diego is diagnosed with septic shock, started on IV antibiotics. Diego is admitted to the intensive care unit, a central line placed, and pressors administered. With blood pressure continuing to drop, and history of abdominal pain with no positive urine cultures, Diego is taken to the OR for exploratory laparotomy. Diego's abdomen drained large quantities of pus; he had ruptured diverticulitis, resulting in septic shock. After the operation, Diego spent several days in the ICU on pressors and IV antibiotics, then several weeks in the hospital. He was discharged home after several weeks, and continued to require in-home wound care for weeks after that.

In retrospect, it became clear that the white blood cells seen on urinalysis were not due to a urinary tract infection, but due to inflamed bowel resting on top of the bladder. Urinary tract infection, refractory to antibiotics in a 45 year-old man without significant past medical history, should have prompted curiosity and a more aggressive work-up at the time of first presentation to the PCP. Had Diego not had developmental disability, urinary tract infection in a healthy 45 year-old man surely would have prompted a more thorough work-up right from the start. But, because Diego has developmental disability, the apparent UTI did not stimulate the PCP's curiosity enough to prompt more of a work-up, even when the urine culture and Diego's response to a course of antibiotics suggested that there was more going on here. The tragic thing, of course, is that a great deal of suffering and expense could have been prevented by more aggressive work-up earlier on.

Case 3: Temisha is a 4 year-old girl with autism spectrum disorder, presenting for comprehensive developmental assessment to an interdisciplinary child development referral center. She has long-standing history of chronic severe constipation, with associated stool withholding, and sometimes, some blood with passage of stool. She has episodic diarrhea, alternating with constipation. Temisha is severely irritable, and spends much of each day in fetal position. She participates little in daily activities at preschool or home. She misses a great deal of developmental preschool programming as a result of this chronic discomfort. Abdominal X-ray shows rectal stool impaction. Constipation is treated with dis-impaction, with large doses of stool softener, given orally, over 3 days. Soft stools are maintained with low-doses of stool softener daily for 1 year. Also, behavioral program of 5 min toilet sits, 4 times daily, is prescribed, to achieve regular pattern of soft, formed stools, 1–3 times per day. Over the next few months, behavior is greatly improved. Strong developmental progress is seen over the next few months, in association with improved bowel pattern. Family believes that Temisha's very dramatic progress is due to the "cleansing of her body of toxins" by the stool softeners.

This case illustrates how a common secondary condition can greatly exacerbate functional limitations in a person with a developmental disability. It also illustrates the importance of thorough review of symptoms in children with severe functional limitations, and the dramatic improvements in function that may be seen when secondary conditions are addressed. At the time of Temisha's presentation, she had already been suffering for years with chronic constipation, and had been presenting with classic physical and behavioral symptoms of this secondary condition. It is sobering to consider what the course of

Temisha's development, and of her life, would have been, had the severe chronic constipation continued to have been ignored.

Case 4: Oanh is a 27 year-old woman with intellectual disability, autism, and multiple congenital anomalies, associated with chromosomal deletion. She has long-standing history of self-injurious behavior. Specifically, she often moans and punches herself in the chest, frequently, all throughout the day. Various primary care providers throughout her adolescence and early adulthood continue to attribute this behavior to self-injurious behavior associated with autism. Various anti-psychotic medications and mood stabilizers had been tried, with various side effects, and without much reduction in the self-injurious behavior. At age 27 years, Oanh presented for the first time to an interdisciplinary center for a comprehensive assessment. The focality of the self-injurious behavior was suggestive of physical discomfort in the chest. Acid damage to the back molars and halitosis suggested possible gastro-esophageal reflux (GERD). A work-up was initiated. A Ph probe demonstrated severe gastro-esophageal reflux disease. Subsequent imaging showed a vascular anomaly restricting the duodenum, causing the GERD symptoms. Surgical intervention was successful in treating the GERD and produced resolution of the self-injurious behavior.

As this case, a 27 year-old woman finally being diagnosed with a severe, congenital vascular anomaly illustrates, shows, there are many barriers to the appropriate evaluation of and intervention for secondary conditions in individuals with developmental disabilities. Barriers to evaluation and intervention may be internal or external to the person. Barriers are often a result of the interaction of the person with his or her environment. Environmental barriers can include physical barriers, social, or attitudinal barriers, and policy or system barriers. Physical barriers are the most visible ones, particularly if the individual has mobility limitations. The social and attitudinal barriers can be harder to recognize. For instance, a health care provider without adequate experience with people with disabilities might be impatient with someone with a disability for being slower at answering questions, completing basic reading tasks, or looking "different". Health care providers themselves can unwittingly be a barrier to the evaluation or and intervention for secondary conditions.

Attitude of Clinicians

The greatest of the barriers to evaluation and treatment of secondary and other conditions might well be the unexamined perceptions of providers. As is illustrated in the cases above, it is all too common for providers to attribute behaviors which might point to treatable secondary conditions to being mere "behavioral problems" or attributable to the primary condition, to be handled by mental health providers, or not requiring intervention at all. Unfortunately, when this happens, mental health providers all too often over-rely on the use of medications, which fail to address the underlying secondary condition, and may actually exacerbate the condition. In the case of Oanh, the use of anti-psychotic medications to treat her "self-injurious behavior" may actually aggravate the situation, by causing obesity, which increases GERD symptoms, or by causing sedation and/or prolactinemia, which worsens irritability. When individuals have developmental disabilities and unusual or problematic behaviors, it is all too common to attribute all behaviors to being "part of the disability", rather than being thorough and curious and taking the time to investigate secondary conditions that may be the cause of these behavioral symptoms [17, 18]. Particularly, as in the Oanh's case, it is tragic when other physical signs and symptoms, such as dental acid damage and halitosis, are ignored for decades, allowing tertiary conditions, such as Barrett's esophagus, to develop. As

discussed elsewhere, due to communication problems, which interfere with obtaining information by interview, and due to mobility problems, which interfere with the physical examination, patients with developmental disabilities need more, rather than less time, to allow for thorough investigation of secondary conditions. Unfortunately, due to unusual behaviors, which some health care providers may find off-putting, data gathering and examination may actually be more cursory for individuals with developmental disabilities than for patients without disabilities.

Health Insurance

Barriers to thorough exploration of potential secondary conditions may also be attributed to the policy of insurers. Although some time limitations for examinations and treatment, set by insurers and by demands on health care providers' time, are acknowledged to be necessary, the needs of the person with disabilities do not change because such limitations exist. In this context, it should be emphasized that small intervention strategies can prevent major secondary medical conditions from occurring and can improve function. For example, in Oanh's case, the tremendous suffering and expense of treating esophageal cancer can be prevented by early diagnosis and treatment of GERD. Comprehensive assessment is necessary for conditions to be identified and interventions to be implemented. In addition to comprehensive review of systems and examination, individuals with developmental disabilities must be evaluated and subsequently treated with an integrated approach, focusing both on the person and the context in which he or she lives and functions. This process requires attention to factors beyond the individual, including family or other significant individuals in their lives, neighborhood supports or lack thereof, and community resources. Medical conditions are often created and/or exacerbated by factors external to the person.

Professional Interactions to Overcome Barriers

Young people with disabilities may have less-developed social, communication, and/or decision-making skills, so the interpersonal skills of providers become more important, and more noted when they are absent. The most basic support for people with disabilities is the respect shown by a health provider. One of the most basic ways to establish respect is to address or question a person directly. Health care providers often find it easier to ask questions of a caregiver, family member, or person transporting a younger child or young adult than to ask that person directly. Young people, even children, can usually answer straightforward questions about their lives.

When compared with the amount of time routinely needed to see a person without disabilities, about twice as much time is necessary when seeing a person with disabilities or a member of that person's family [19]. Sometimes, including others for verification or elaboration is important, but the tendency all too often is to overlook the individual with disabilities in the name of efficiency and credibility. Unfortunately, there are significant problems with this all too common approach. For one, the opportunity for the health care provider to build a healing relationship with the young person with disabilities is lost. For another, the opportunity to help a young person with disabilities to develop competency in communication with their health care provider is lost. This, investment of extra time in making an effort to involve a young person with disabilities in the medical interview improves communication and care, and, in the long run, may actually save time and money, as illustrated in several of the cases described above.

Transition from Pediatric to Adult Care

A related issue is the transition from pediatric to adult care. Pediatricians, both primary care and sub-specialists, often are torn between continu-

ing care for young people as they mature to adulthood and acknowledging the limits of their own training, experience, and professional comfort. Crucial in the transition from child to adult health care providers is the reconstruction of resources by the young person and his or her family. This process often requires looking for different medical and health providers, emotional supports, and hospitals because many pediatric medical centers will not admit anyone older than 21 years of age. This change can be particularly difficult for a young adult with disabilities whose pediatric team has not made transition plans and is not on the staff of an adult facility [20]. Again, a case study may help to elucidate this issue.

Case 5: Keith is a 21 year-old man with history of mild intellectual disability and chronic lung disease. His mother is alarmed to find that Keith is becoming progressively more and more fatigued. His academic functioning, in his last year of his transition program, and his hygiene, are beginning to suffer, as his energy flags. Suspecting that these symptoms may reflect an exacerbation in his lung disease, Keith's mother calls the Pulmonary clinic where Keith has been a patient for two decades, to make an appointment. To her great surprise and shock, she is told that Keith will need to transfer care to an adult Pulmonologist, now that he is an adult. Pediatric hospitals often do not provide appropriate preparation for transition to adult care.

In the meantime, while waiting for that appointment, Keith followed up with his developmental-behavioral pediatrician, whose clinic did not have such strict age limits. Keith's mother, accustomed to being the spokesperson for her quiet son, launches into a detailed history of Keith's pulmonary symptoms. The developmental-behavioral pediatrician gently interrupts Keith's mother and asked Keith how he has been doing lately. With some prompts and a lot of patience, the pediatrician eventually elicits from Keith a 2 year history of obsessive compulsive symptoms. These symptoms have been gradually escalating in severity, up until the present. Keith explains that he is up every night for hours, contorting his body and freezing his body into bizarre positions at the side of his bed, unable to sleep. Even without pulmonary function testing, the cause of Keith's escalating fatigue quickly becomes clear.

Medical staff and family, along with the young person, must establish mutual respect, communication, and a relationship that will allow straightforward analyses of issues related to independence during adolescent development. These professional behaviors allow for thorough and complete assessment and evaluation related to secondary conditions of individuals with developmental disabilities. The foundation for promoting health is now established.

Principles of Health Promotion

The WHO defines "health promotion" as "the process of enabling people to increase control over, and to improve, their health. It moves beyond a focus on individual behavior towards a wide range of social and environmental interventions" [21]. The Ottawa Charter for Health Promotion [21] declared that the ability to reach a state of physical, mental, and social well-being, an individual or group "must be able to identify and to realize aspirations, to satisfy needs, and to change or cope with the environment". This goal of helping individuals increase control over their health, with the requisite understanding and actions to improve their health is a critical one for individuals with developmental disabilities. While individuals with developmental disabilities may have impairments in learning, cognition, emotion, or behavior that make these goals challenging, health/medical professionals have the opportunity to promote the health and well-being of these individuals. The final goal of all health care, medical care, and health promotion is that the individual be able to participate in society.

Health promotion services really begin with helping a person with developmental disabilities to become increasingly responsible for his or her own health, consistent with their capacity. Two terms are relevant in this regard. Selfdetermination is usually a long-term goal that may not breached,

whereby the individual with developmental disabilities is able to make most choices for themselves, whether health, education, community-living, or as simple as choosing clothes to wear or food to eat. Self-advocacy, however, is a process by which individuals with developmental disabilities are encouraged to make their wishes, desires, and preferences to be through empowerment. Health care professionals may not keep this goal of self-determination utmost in their clinical thinking. Health promotion, when included, is viewed as providing health-related information—from the professional to the individual. Sound bites of accumulated wisdom are presumed to provide the knowledge and incentive for healthy behaviors to begin and continue. A clinician can encourage self-advocacy in any appointment or interaction by willingness to engage the individual on their level, even if it takes more time.

Although people with developmental disabilities are usually quite willing to listen to authority figures such as medical professionals, as are most of the general population, they may have difficulty comprehending the message. If comprehension is not a problem for the individual, the person still may experience memory problems or difficulty keeping a sequence of instructions in the order necessary for them to be of help. Video or written guidance may be used as an adjunct to any verbal interaction or direction. Frustration tolerance can be sufficiently low that, if barriers arise, the whole message can be lost. Yet, guidance toward healthy behaviors provides the greatest opportunity for health care providers to be oriented beyond just medicine and toward health.

Counseling is, by definition, two-way in nature—that is, an exchange between or among individuals. Counseling connotes mutuality, rather than more directed terms such as guidance or teaching. In view of the secondary conditions discussed earlier-poor conditioning, obesity, oral health problems, and so forth-counseling to promote health behaviors and prevent secondary conditions is extremely important, particularly in the areas of physical activity, healthy diet, and tobacco use. Unfortunately, the time required for appropriate counseling interaction on health behaviors is extremely limited during routine clinical visits. It is all but prohibitive if an individual requires more attention, as is often the case with people with developmental disabilities. In addition, such health promotion services are not always covered by insurers, despite the fact that many insurers use prevention as a major thrust of marketing for their plans.

One facet of counseling that is often overlooked involves the discussion of exploitation. From childhood onward, people are vulnerable to being manipulated by others who are more cognitively adept and more emotionally hardened. Whether the outcome of the exploitation involves money, time, work, or even sex, individuals with developmental disabilities are of a more trusting nature, without guile, and therefore more vulnerable to manipulation. Health care providers can offer both the perceived authority and the sense of personal safety to allow someone with a developmental disability to disclose information about being taken unfair advantage of by others.

Another aspect of health promotion emphasizes the need for clinical preventive services. Clinical preventive services traditionally include screening tests, immunization, and counseling [22]. Because counseling can, and often does, overlap into health promotion services, it is discussed in that context in this section. A study by Jones and Kerr [23] indicated, however, that individuals with cognitive impairments did not receive annual health screenings. The Guide to Clinical Preventive Services [19] from the US Preventive Services Task Force should be applied to people with developmental disabilities. The recommendations cover 80 primary conditions for which all individuals are at risk. It concludes that, if a segment of the population does not receive the services detailed therein, they are at greater risk for the conditions identified—a straightforward conclusion to draw, but particularly poignant for the population of individuals with developmental disabilities. Of those preventive services provided by the Task Force, most relevant for individuals with developmental disabilities would include coronary disease, cancer, metabolic and nutritional disorders, vision and

hearing disorders, emotional problems, and substance abuse.

Screening for emotional problems in both children and adults with developmental disabilities is critical given the magnitude of this problem. The Healthy People 2020 chapter called "Disability and Secondary Conditions" provided two objectives aimed at reducing depression among children and adults with disabilities [24]. Data for that report from the National Health Interview Survey indicated that 17 % of children without disabilities are reported to be sad, unhappy, or depressed, whereas 31 % of children with disabilities report these emotional problems. Likewise, 28 % of adults with disabilities report that depression prevents them from being active, whereas only 7 % of adults without disabilities report the same.

Providers may mistakenly conclude from a routine visit that nothing untoward is occurring emotionally for an individual because the problem is not evident. Observational skills notwithstanding, providers need to ask about emotional issues. Although screenings for emotional problems might be routine in most practices for most children or adults, people with developmental disabilities often seem to slip through the clinical cracks. One problem is that commonly utilized standardized screens for emotional conditions are not standardized for individuals with disabilities. These screens often depend on literacy, insight about feelings, and/or ability to describe these feelings, abilities which may be impacted in some disabilities.

Case 6: Luisa is a 20 year-old woman with Down syndrome, who was quite high functioning, conversant, frequently meeting with friends, enjoying a number of hobbies, until she started a slow decline over the last couple of years. Parents, alarmed by this decline, brought her to a Genetics specialist for a consultation, 2 years previously. The consultant concluded, without the benefit of any tests, that this decline in function represented early onset alzheimer's disease. The loss of function has persisted and parents pursue a second opinion through an interdisciplinary Down Syndrome Center. The specialists at the Down Syndrome Center note that Alzheimer's disease is more common in Down syndrome than in the rest of the population, but that this is due to the fact that Alzheimer's disease presents about 20 years earlier in Down syndrome than in the rest of the population. It is noted that Alzheimer's is virtually unheard of in 20 year-olds with Down syndrome, prompting a more aggressive work-up. Screening of emotional state yields symptoms consistent with depression and obsessive compulsive disorder. Sleep study finds quite severe obstructive sleep apnea. Treatment of these conditions produces significant improvement in functioning over the next year.

Enhancing Function

A relatively new classification addressing function which complements the diagnostic classification, ICD, has been approved by the World Health Organization. The International Classification of Functioning, Disability, and Health (ICF) [25] outlines three dimensions of function and analogous levels of difficulty—body functions/impairments, activities/activity limitation, and social participation/participation restrictions. The ICF provides the conceptual and coding to operationalize these concepts. All of these, however, are influenced by the novel dimension added to the ICF by WHO—environmental factors.

Environments Can Be Either Barriers or Facilitators

Environmental facilitation to reduce or prevent secondary conditions can be seen as the outer boundary of clinical practice. Personal assistive technology, however, is routinely provided for vision and hearing impairments in the general population. These devices are so ubiquitous that they are not commonly viewed as disability related, but simply a part of functioning. For example, assessing what assistance should be

provided to keep impairments (body function problems) such as refractive vision impairment from becoming personal activity limitation (seeing clearly enough to read) or participation restriction (seeing well enough to drive in the community) is considered standard medical care.

In contrast, other assistive technologies, which have the capacity to ameliorate impairments of people with developmental disabilities, and thus to reduce limitation and improve participation of these individuals in the community, are not as universally accepted as part of health care. Newer technologies, such as smart-phones, with various applications, are used by a growing segment of the population to organize their lives. Use of these devices and applications by individuals with developmental disabilities, including cognitive impairments, has the potential to increase community participation substantially. Features such as basic social cues, simple directions (perhaps based on global positioning features), mathematical computation abilities, or emergency procedures can be including, using symbols, signs, oral instructions, or written material, according to level of functioning of the individual. These devices have applications for what is generally considered to be "health-care", such as reminders to take medications, or reminders of doctors' appointments. In a broader conceptualization of "health care", though, these devices and applications can be seen to foster health in people with developmental disabilities by increasing community participation, which, in turn, reduces secondary conditions, such as depression, agoraphobia, and physical deconditioning, which impact physical health as well.

Case 7: Billy is a 4 year-old boy with quadriplegic cerebral palsy. He arrives to developmental pediatrics clinic with his mother pushing him in an umbrella stroller. During the interview, he is constantly sliding out of his seat, and his mother must keep adjusting his position to keep him from falling out of the stroller. During assessment, he is placed in chair with appropriate trunk supports. His mother is amazed to see how well he is able to use his arms when his trunk is thus stabilized. Mother explains that prescription for wheelchair has been denied by insurance yet again. When mother spoke with person in authorization office, she was advised to "just go get a used wheelchair from a nursing home".

Sadly, this case, like all the others in this chapter, is not fictionalized, except for the name of the child. For children with cerebral palsy, and other children who lack postural control, wheelchairs function as more than just a set of wheels for carting around the child. The postural support offered by a quality, customized wheelchair, by stabilizing the child, allows the child to develop upper body coordination, eventually toward a goal, perhaps of controlling their own power chair and increasing independent mobility and inclusion. The postural support also helps to prevent aspiration, which may occur with less support, and, of course, may prevent injury that may result from falling out of an inappropriate chair or stroller. Ironically, a chair may be paid for many times over for the same cost as hospitalization for aspiration pneumonia, let alone head injury.

Germane to this discussion is the issue of funding for technology to assist people with developmental disabilities. Medical necessity is the term used by health care professionals to describe the need for various kinds of assistance for restoring function, reducing disease, or restoring physical equilibrium, such as a wheelchair for a person with a mobility limitation or a voice synthesizer for somewhat with limitations in vocal communication. Determinations are based on the notion that such assistance is needed for improved function—at the level of body functions and structures, using ICF descriptions. The definitions used by third-party payers, however, often differ from those used by health professionals in practice [26]. As commonly used, the use of medical necessity as a criterion denies needed services to individuals with disabilities. For example, though an individual with limitations in vocal communication may need an augmentative communication device to be able to communicate with their health care provider, as well as for broader communication which sustains overall

mental and physical health, requests for such technology are often not authorized by payers. Similarly, people who rely on wheelchairs for long-distance mobility are often refused authorization of payment for wheelchairs if they have limited ability to ambulate, such as within their home. However, failure to authorize such equipment impacts community participation and reduces opportunity for social interactions which are, ultimately, essential to health and well-being.

Many people with cognitive impairments do not need the kinds of assistance routinely covered by the medical necessity criterion. They might, however, need accommodations at home to increase safety or independence or health maintenance programs. These and other needed services are important for might be called health necessity. Health necessity describes the services for maintaining function, preventing secondary conditions, increasing functional independence, and equalizing opportunity for participation. Rehabilitation, even, is at times not deemed a medical necessity except as it serves to restore function. In cases of developmental disability, where rehabilitative services, including therapy and equipment, may serve to maintain function at current level, but cannot be reasonably expected to restore or improve function, payers often refuse to cover such services and equipment. Tragically, this may lead to loss of function that otherwise would have been preventable. Clinical practice, therefore, should be vigilant that all possible health necessities are explored for people with developmental disabilities.

Maintaining function and increasing independence to decrease secondary conditions also should be part of the prescription for well-being for these individuals. Care should be taken, however, because the network that maintains assistive technology often is fragmented, the result being technology that is present but nonfunctioning. Under these circumstances, the environmental facilitator becomes a barrier, capable of creating secondary conditions for the individual or family. Fundamental to the success of any environmental facilitator is access, whether to a medical service coordinator, a technological device, or a personal assistance device. Creativity is a needed characteristic for health providers, finding ways to connect the individual with the needed supports. Over time, the financial benefits as well as the individual functioning are validated.

Interdisciplinary Approach

Finally, the concept of teamwork has focused on one of two notions—the "team" is all of the varied medical specialists involved in a an individual's care or the "team" is a group of individuals from varied disciplines (including possibly nursing, social work, speech language pathology, occupational therapy, physical therapy, psychology, recreation therapy, and nutrition) who contribute to the individual's well-being and the well-being of the individual's family. In the current environment, both approaches to teamwork have suffered. For coordinated interdisciplinary teams to function, time must be allocated for the team members to actually coordinate care. Billing for medical care is usually authorized only for face-to-face patient care, so that funding is not provided for team coordination. In the current climate, with stretched budgets, coordination of care is often cut. As is illustrated in the case of Luisa, these teams are well worth funding, as such teams can be essential to the discovery of treatable secondary conditions, promote health, save money, and prevent suffering.

Conclusions

Allan Myers [27] reported studies showing a direct relationship between the number of secondary conditions reported and happiness, thus highlighting the relationship between health and happiness. He concluded that if individuals with developmental disabilities are to move toward health, there is a need for "greater professional humility to appreciate that people with both physical and intellectual impairments are able to experience and articulate their own satisfaction,

pleasure, and joy". Medicine is a crucial component of health, but health is more than medicine.

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Section 3

History

History of Health Care for People with Intellectual and Developmental Disability

3

Wendy M. Nehring and Brandi Lindsey

Abstract

The history of health care for people with intellectual and developmental disability (IDD) shares similarities with the general population, but is composed of inequalities, a lack of access, poorer quality, and higher costs. This chapter will explore this history through a discussion of major issues.

Introduction

The history of the health of and health care delivery for people with intellectual and developmental disability (IDD) has loosely paralleled that of the general public, but the inequality that exists for this population remains today and continues to influence persistent issues of access, quality, knowledge, and communication. The themes of terminology and classification systems, knowledge of IDD, forms of health care delivery, education of health care professionals in the field, research, and federal influences will be chronologically discussed leading to a final section on future considerations. The history of this population is important and detailed and will only be highlighted in this chapter. Attention is placed on the history of health care for people with IDD in the United States. For a richer discussion of the history of people with IDD, we recommend that you read Scheerenberger [1, 2], Trent [3], Sloan and Stevens [4], Nehring [5], Schalock et al. [6], and Schalock et al. [7].

Terminology and Classification Systems

Over time, people with IDD have been labeled with a number of negative terms. In the 1800s and early 1900s, the common terms were feebleminded, mental defective, imbecile and idiot. Two early classification systems with different numbers of categories, published by physicians, Ireland and Kerlin in 1877, were based on dis-

W.M. Nehring, RN, Ph.D., FAAN, FAAIDD (✉)
College of Nursing, East Tennessee State University, 365 Stout Dr, Johnson City, TN 37614-1709, USA
e-mail: nehringw@etsu.edu

B. Lindsey, RN, MSN, CPNP, Ph.D.
School of Nursing, Middle Tennessee State University, 1301 East Main Street, Murfreesboro, TN 37132, USA
e-mail: Brandi.Lindsey@mtsu.edu

I.L. Rubin et al. (eds.), *Health Care for People with Intellectual and Developmental Disabilities across the Lifespan*, DOI 10.1007/978-3-319-18096-0_3

ease [8, 9]. Physicians at this time believed that IDD was caused by either congenital or accidental causes leading people to believe that persons with IDD were born to couples with disreputable or undesirable backgrounds (e.g., alcoholics and prostitutes). Family pedigrees (most notably the Kallikaks and Jukes) influenced these beliefs. Such thinking led to the eugenics movement, lasting several decades, in which a level of normalcy was expected to function in society; people deemed to be "abnormal" were segregated. This period represented one of the lowest points in our understanding and care of persons with IDD [10].

In the 1920s, intelligence or IQ testing became the norm and often, the sole criteria for diagnosis of IDD. Such testing came about due to society's feelings about eugenics and influenced by Darwin's theory of evolution. Not only did these assessments affect the lives of persons with IDD, but also many immigrants, new to the United States, who did not speak English well or at all and many people were therefore misdiagnosed [11, 12]. Interestingly, Morgan in 1925 called for a classification system without categories, but it took approximately 70 years for this idea to be realized [13].

By the 1930s, the label for IDD was mental deficiency and was classified into three categories: idiot, imbecile, and moron. IQ continued to be the primary determinant for the diagnosis of one of the above labels, but for the first time, other factors, such as behavior, emotional reactions, and background history were considered [4].

The first diagnostic and statistical manual of mental disorders (DSM-1) was published by the American Psychiatric Association [14] in 1952 and classified mental deficiency into three categories: mild, moderate, and severe, based on IQ. These categories prevailed throughout the century.

In 1961, IDD was referred to as mental retardation and the definition included two factors, developmental period and adaptive behavior, in addition to IQ. The classification categories were also enlarged to five: borderline, mild, moderate, severe, and profound. Borderline was removed in the next edition of the classification system in 1973 [2]. In the next editions in 1973 [15] and 1977 [16], the authors differentiated genetic from social and environmental causes.

A new term, developmental disabilities, arose during the decade of the 1970s. In the definition of mental retardation, the diagnosis must come prior to or at age 18 years. In the definition of developmental disabilities, the age of diagnosis can be up to age 22 years. Adaptive behaviors are also more detailed in the definition of developmental disabilities and the definition includes a broader umbrella of physical and/or mental conditions. What is most interesting about the establishment of the clinical term, developmental disabilities, is that it was coined for purely political reasons. The laws that Kennedy put into place were due to be renewed or refunded in the 1970s, but due to his dislike of the Kennedys, then President Nixon would not renew these laws unless a new term was introduced, as he felt mental retardation was a term directly linked to the Kennedys [5].

In 1980 the World Health Organization [17] introduced the "International classification of impairments, disabilities and handicaps." This classification system highlighted diseases and disorders and the functional impact on the person. Mental retardation and developmental disabilities were considered disorders.

The classification of mental retardation in 1992 underwent significant changes. Instead of IQ, the diagnosis of mental retardation was based on level of functioning and the term was changed to intellectual disability (ID). The decision to change the term came about through the combined advocacy of professionals, family members, and significantly, persons with IDD, with the mission to identify a less negative term. To determine level of functioning, four dimensions had to be assessed: (a) intellectual functioning and adaptive behaviors, (b) psychological and emotional status, (c) physical health, and (d) environmental factors. Strengths and limitations for each dimension were identified as well as existing informal and formal support systems, and long- and short-term support needs. Cultural and environmental backgrounds were also delineated in this assessment. The categorical system

of classification based on IQ was eliminated by Luckasson and colleagues [18] for the American Association on Mental Retardation (AAMR). In response, the American Psychological Association published their own definition and classification system which maintained the IQ categories [19].

The most recent definition of IDD keeps the three criteria of "significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills, and age of onset before age 18 years" ([7], p. 13). The current conceptual framework of human functioning which serves as the foundation of the definition has been revised for this edition and includes five dimensions: (a) intellectual abilities, (b) adaptive behavior, (c) health, (d) participation, and (e) context.

The World Health Organization publishes the "International classification of diseases" (ICD) and is developing the 11th edition now even though the 10th edition is being launched. Intellectual disability is now widely recognized as the preferred term. The World Health Organization has tried to meld their previous classification with this new term and have proposed "intellectual developmental disorders." The American Association on Intellectual and Developmental Disabilities (AAIDD, formerly AAMR) is very much against this terminology and brought together experts in the field to develop a response. They have recommended "disorders of intellectual and developmental disability" [20]. Wehmeyer [21] noted that if IDD is eliminated from the ICD, the opportunity for people with IDD to receive needed health resources is compromised.

The latter decades of the twentieth century also saw the use of more specific terms to identify, define, describe, and use in place of the more general terms of mental retardation, developmental disability, or now, intellectual and developmental disability. Such terms were emotional disorder, learning disabilities, behavioral disorders, and dual diagnosis [22]. Across time, changes in terminology and classification have been dictated by political, social, and economic reasons. For excellent, in-depth discussions of the history of the definition and classification of IDD, see MacMillan and Reschly [23]; Odom, Horner, Snell, and Blacher [24]; and Schlock et al. [7].

Knowledge of Intellectual and Developmental Disability

As knowledge of diseases grew over time, so did the medical understanding of IDD. This can best be illustrated by the understanding of the etiology of IDD over time (see Table 3.1). In 1892, Down [28], who described trisomy 21, also known as Down syndrome, once suggested that ethnicity played a role in IDD, but quickly dismissed this idea. Even so, Down syndrome was mislabeled as "mongolism" for many years. Also in 1892, Shuttleworth [29] first classified the etiology of IDD by prior to birth, at birth, and after birth.

Significant advances in medical knowledge, techniques, and treatments took place in the next several decades that helped to change understanding of IDD. The 1930s saw improved understanding of etiologic conditions of IDD based on new knowledge of genetic conditions, such as phenylketonuria (PKU). Better obstetrical care and delivery methods, development of immunizations and medications (such as sulfa, penicillin, other antibiotics, anticonvulsants), use of dietary supplements (eg., folic acid), regular physical examinations, use of x-rays, understanding of Rh incompatibility and endocrine conditions, and better medical and surgical techniques based on increased knowledge of infection, anatomy, and physiology took place during the 1940s and 1950s [25, 30, 31].

In the second half of the twentieth century, significant medical advances included treatment of prematurity, further development of medications (including psychopharmaceuticals) and immunizations, gene therapies, and newborn screening techniques. The development of laboratory tests and radiologic equipment assisted health professionals to better assess and diagnose conditions resulting in IDD [32].

Table 3.1 Evolution of understanding of etiology of IDD

Common thinking of prominent physicians in late 1800s [25]	Scheme for etiological study (1903) [4]	Etiologies of mental retardation in 2005 [26]	Etiology of global developmental delay and IDD (2008) [27]
Accidental causes Instrumental or other forms of birth accidents Diphtheria, German measles, infantile paralysis, measles, meningitis, scarlet fever, or tuberculosis Drugs, such as opium Epilepsy Alcoholism Chorea Goiter and cretinism Congenital Factors Family history Emotional shock and insanity Alcoholism Consanguinity Tuberculosis Epilepsy Goiter Syphilis Cancer Illegitimacy and attempted abortion	Before labor Alcohol Parental health (e.g. tuberculosis or syphilis) Heredity Health of father at conception Maternal injury during pregnancy Maternal, anxiety and grief during pregnancy Diseases of uterine or placenta Abnormal cerebral development-unknown origin Infrequent cretinism During Labor Instrumental Trauma Non-instrumental Trauma After Labor Disease Trauma	Prenatal causes, e.g. Known genetic conditions Multifactorial causes Acquired conditions, such as alcohol, drugs, and teratogens Perinatal causes, e.g. Birth trauma Metabolic abnormalities Hypoxia Infections Intracerebral hemorrhage Postnatal causes, e.g. Infections Trauma Extreme malnutrition Unknown causes	Chromosomal anomalies or genetic syndromes Intrapartum asphyxia Cerebral dysgenesis Early extreme psychosocial deprivation Antenatal toxin exposure

The importance of secondary conditions to living with an IDD was first discussed in 1978 [33], but only in the last decade have secondary conditions received appropriate attention in order for health professionals to provide better, comprehensive health care. Over the past several years, secondary conditions and their prevalence have been documented in the literature as well as conditions that are not as prevalent as in the general population for a given condition. For example, individuals with Down syndrome have reduced incidences of caries, certain cancers, and myocardial infarctions, but increased incidences of heart defects, upper respiratory conditions, and intestinal problems based on medical histories [34]. Kositsas and Iacono [35] found an average of 11.3 secondary conditions in their study sample of caregivers of 659 individuals with IDD. The most frequent secondary conditions found in recent research using caregivers were communication difficulties, reading difficulties, physical fitness conditioning, weight problems, and personal hygiene issues [35, 36]. It is interesting that caregivers identify quality of life issues as more important than physical conditions.

In the last decades of the twentieth century new understanding of how environmental factors resulted in IDD received needed focus. The primary etiological diagnoses to receive attention were congenital HIV infection; conditions causing IDD that result from maternal drug abuse, and child abuse. Homelessness in children also impacted normal development and came to the attention of health professionals [37] as did neurointoxicants and chemicals [32, 38, 39].

In the early years of the twenty-first century, it is widely recognized that genetic causes represent about 50 % of all causes of IDD based on advances in genetic knowledge, laboratory testing, and radiographic imagery. Laboratory studies allow for diagnosis in many more cases and include FISH subtelomere study, molecular genetic test-

ing, metabolic testing, and/or fragile X genetic testing. Radiographic studies, such as MRIs may also be done to confirm diagnosis [27].

The advances in our knowledge of IDD and how these conditions affect the lives of people and their families continues to be critical to the delivery of health care. While our knowledge has grown greatly over the years, a new understanding and synthesis of known information will be essential as we move forward.

Health Care Delivery

Current understanding of disease processes and societal views have influenced the care of people with IDD over the years. Early descriptions of the care of this population focused on religious orders and humanitarian care prior to the nineteenth century [1]. As understanding of diseases and their symptomatology grew in the nineteenth century, the care of people with IDD changed with the eugenics movement and became custodial in the latter half of the century. Individuals, who were deemed abnormal, were often housed together under primitive conditions; often in asylums [1, 5].

The period from 1900 to present time can be divided into three paradigms. The first paradigm has been referred to as the institutional paradigm and lasted from 1900 until 1970 and was followed by the institutional reform (1970–1980) and community living (1980 to present) paradigms [40].

Institutional Paradigm

By the first few decades of the twentieth century, institutions designed to house large numbers of people were built. In order to separate these buildings from the general public, they were often built outside of the city and located away from the public. The conditions grew to be deplorable with overcrowding. The care became largely custodial due to the large numbers of people and declining resources [41]. After WWII, families were encouraged to place their children in these institutions and often when a child with IDD was born and diagnosed at birth, the child was taken immediately to the institution and either the mother was told that the child had died or the parents were told to tell others that the child had died. This practice and the large numbers housed in institutions continued for several decades [3, 5, 32].

The traditional medical model with physicians making all health decisions was the norm for many years. In the 1940s, after much was learned from the mental health concerns of returning soldiers in WWI, the mental health team emerged which used multidisciplinary care. The field of mental deficiency, at that time, adopted this method of health care. The physician remained in the lead, giving the orders to nurses and other disciplines, such as social workers, radiologists, and laboratory personnel, but also conferring with each member. The physician then summarized all information and presented his or her diagnosis and plan of care to the patient's family if they were involved and to the team [37, 42]. Health care was delivered primarily in the institutions in a clinic or hospital on the grounds [43].

In the 1950s, child guidance clinics and developmental diagnostic clinics arose. Children with IDD remained at home until school age when they were referred to institutions. Care focused on activities of daily living and physicians and nurses provided parents with instructions on preventive health care, communicable diseases, appropriate moral behavior, and well-child care [4, 44]. Institutional care remained poor due to nurse-to-patient ratios of 1:400 [45].

The care of people with IDD in institutions altered dramatically in the 1960s and 1970s with the publication of Christmas in Purgatory [46] in 1966, a revealing photographic essay of the conditions in institutions and the national television broadcast by Geraldo Rivera at Willowbrook Institution in New York in 1972 [5]. The public could no longer deny the care given to a percentage of the population and the deinstitutionalization movement began.

Institutional Reform Paradigm

In Denmark Niels Erik Bank-Mikkelsen (1919–1990) and in Sweden Bengt Nirje (1925–2006) in 1969 [47] introduced the concept of normalization stating that everyone deserved the right to live the best life possible with common choices concerning, for example, food, living arrangements, and social interactions. Wolf Wolfensberger (1934–2011) [48] a German-American, expanded the concept and discussed behavior and personality. His writings greatly influenced deinstitutionalization and community living and influenced the developmental model which outlined the need for care across the lifespan [2].

During the 1960s, health care became more interdisciplinary with many disciplines, including nurses, psychologists, nutritionists, social workers, physical therapists, etc. collaborating together as a team with different disciplines taking the lead when necessary [37, 42]. Health care was delivered in the community, in institutions, and by the close of the 1960s, in "intermediate care facilities for the mentally retarded" (ICFs/MR) that served 4–24 persons [43].

Community Living Paradigm

The transition to the community came slowly as families became reacquainted with members that they either did not know existed or saw infrequently, models of care delivery had to be developed, and intermediate housing arrangements (eg., ICFs/MR) and group homes were built or acquired [32]. Many changes came about as a result of the move to community living, including lifespan care, a greater focus on transition to and care of adults with IDD, further development of models of health care delivery, professional scope of practice, health care guidelines, federal white papers calling attention to the needs of people with disabilities, and self-determination. Some people with IDD remained in institutional settings, now called developmental centers. Individuals were likely to have more severe disabilities with physical, behavioral, and/or mental health limitations. In 2009, there were 20,710 individuals living in congregate care settings as compared to the high of 193,200 in 1967 [49, 50].

The need for increased attention to the care of people of all ages with IDD in the community became important. In the past, children with genetic conditions associated with IDD often did not live into adulthood. Knowledge about such conditions focused only on infancy and childhood. With advances in knowledge concerning disease conditions, treatments, and therapies, people with IDD lived longer and by the 1980s, transitional care from pediatric to adult care and care of the adult and older adult with IDD was needed, including health promotion for normal aging [51–53] and planning for and providing end-of-life care [54].

Adult clinics were established where only child-based clinics had existed previously. These clinics were often found in children's hospitals and staffed by pediatric personnel as, at that time, pediatricians felt that they were best qualified to care for adults with IDD. In 1987, Ziring [55] described the first primary care medical home for people with IDD of all ages in New Jersey. Physicians and nurse practitioners began to play pivotal roles.

Transdisciplinary care was introduced in the 1980s where boundaries between disciplines were relaxed and several members of the team performed similar skills. Haynes described this as role extension, role exchange, and role release [56]. This method of care delivery was popular in early intervention for infants and children ages birth to 3 years with IDD [57], but has not remained popular over time. Interdisciplinary care remains the more common practice.

In the 1990s, managed care was introduced [58]. While this model of health care changed how health care was delivered and funded, it provided positive and negative effects on the care of people with IDD. Positive changes included case coordination, cost savings based on efficiency of services [59, 60], and the need for standards of care. This was the first time that the triple aim of quality, access, and cost were discussed together. The negative aspects of this model of care included: (a) the lack of access and support for

comprehensive services that included social services, respite, housing needs, and transportation; (b) the inability to assign capitation rates to these services [59] and high costs for services [61]; (c) the decreasing ability to use preferred providers; (d) lack of expertise in IDD for listed providers; (e) reduced quality of care; and (f) lack of coordination for chronic conditions across time [62–64].

The scope of practice and standards of care for people with IDD has primarily been defined for nursing. Beginning with the "Standards for state residential institutions for the mentally retarded" [65], these standards have evolved according to general nursing and specific specialization roles and responsibilities. The most recent publication is the "Intellectual and developmental disabilities nursing: Scope and standards of practice" in 2013 [66].

Health care guidelines for specific conditions were developed and published and assisted the physician and other members of the healthcare team with protocols for developmental care. One of the first guidelines to be published was "Health care guidelines for individuals with Down syndrome" [67]. For a more detailed discussion of types of guidelines of use in the health care of IDD, see Nehring and Betz [32]. More recently, Sullivan and his colleagues [68] published "Primary care of adults with developmental disabilities: Canadian consensus guidelines" based on research and best practices. Although developed for Canadians, these guidelines are globally applicable. National guidelines for a variety of conditions, including the "Massachusetts Department of Developmental Services adult screening recommendations 2012" [69] can be found online.

Healthy People 2010 [70], a national blueprint for health, devoted a chapter to disability and called for a standardized definition of disability. The most recent Healthy People 2020 [71] expanded on the 2010 recommendations to improve the health of people with disabilities. In 2002 and 2005, the Surgeon Generals held conferences and published white papers on the care of people with IDD [72, 73] after a call to attention by Eunice Kennedy Shriver (sister to President Kennedy) and her son Tim Shriver, and their colleagues at Special Olympics [74]. These documents focus on health promotion noting that people with IDD are at risk for sensory deficits, obesity, mental health problems, oral health issues, and poor physical conditioning; the need for an increase in knowledge about disability and living with these conditions; the need for increased quality of health care, the need for increased efforts toward health care professional training, adequate funding to produce positive outcomes, and an increased need for comprehensive services.

Self-determination became an important new term to describe the individual's right and ability to determine their own decisions regarding all aspects of life, including health care. This idea precipitated new thinking to include the individual with IDD in all aspects of health care decision-making and an important update to the concept of normalization [43].

Today, people with IDD of all ages and ethnicities are found in every setting, including schools, day care, interdisciplinary clinics, hospitals, out-patient settings, senior settings, subsidized housing, group homes, nursing homes, etc. Even so, many barriers exist including a lack of access to health professionals (e.g., mental health and dental), communication difficulties between the person with IDD and the health professional, limited appointment times, lack of access to needed health facilities, lack of necessary examination equipment, lack of knowledge and attention to women's and men's health issues across the lifespan for people with IDD, lack of access to culturally competent care, and lack of access to other means of accommodation (e.g., sign language interpreters) [75–78].

Opportunities for health professionals to identify, plan, implement, and evaluate comprehensive, coordinated team care and reduce barriers are numerous, but often not realized. Physicians have noted that they are sometimes "operating without a map" when caring for people with IDD due to a lack of knowledge and experience ([79], p. 243). Continuing education opportunities for all health professionals are imperative to counteract this feeling.

Education of Health Care Professionals

The first formal education of health professionals, primarily physicians and nurses, in the care of people with IDD took place in asylums beginning in the nineteenth century. Nurses specialized in "mental nursing" which covered IDD and mental illness. Education was similar to that in general programs of medicine and nursing, but included specific therapies used with this population, such as hydrotherapy [80, 81]. The national curriculum for nursing in 1926 included information on IQ; mental testing; definitions, classification, and etiology of IDD; colonies and institutions; legislation, and care and education [82]. There was little change in the education of physicians and nurses concerning this population until the 1960s.

The advent of the Kennedy presidency (1961–1963), subsequent legislation, and the discovery of the conditions in institutions, created the availability of funding and resulted in (a) a national emphasis on the education and care of persons with IDD; (b) research into the prevention, causes, and treatment of conditions resulting in IDD; and (c) education of health professionals in this emerging field. Reflecting the growing knowledge of IDD and the advances in health care, physicians and nurses working with people with IDD were required to have knowledge of genetics, embryology, normal and abnormal development, nutrition, microbiology, prevention screening, and psychology [83].

Attention to IDD content in textbooks has waxed and waned over the years. Publishers, like Paul H Brookes Publishing and PRO-ED once offered a vast collection of books on a variety of educational, social, and health related topics related to IDD. In recent years, there are fewer books available as interest has declined. The American Association on Intellectual and Developmental Disabilities (AAIDD) today offers the largest collection of books and materials on IDD. Federal funding for the development of core curriculums for the health disciplines is lacking [76]. Only one core curriculum was published and it focused on nursing [84].

Today, opportunities for clinical education concerning the care of people with IDD and time for didactic content have varied depending on faculty interest and availability. Universities where a University Center for Excellence in Developmental Disabilities (UCEDD) is present have provided increased faculty expertise and opportunities for student interaction. The American Association on Intellectual and Developmental Disabilities (AAIDDD), the Developmental Disabilities Nursing Association (DDNA), the American Association of Developmental Medicine and Dentistry (AADMD), and United Cerebral Palsy (UCP) are examples of specific organizations that provide continuing education, publications (including curriculums), and at times, research funding opportunities for health care professionals.

Research

Early research in IDD influenced the knowledge of conditions that result in IDD; how to treat such conditions through medication, procedures, and therapies; and what educational and social programs would best benefit daily life. Significant research advances include the discovery of phenylketonuria (PKU) in 1934, the discovery of the double-helix model of DNA in 1953, and the mapping of the human genome in 2001 [32].

Such research advances have also influenced science, technology, and our understanding of ethical and legal issues as they relate to medical advances. Highlights of science discoveries include genetic engineering, gene therapy, new medications, and newborn screening techniques. Technological advances have allowed for more accurate diagnoses through laboratory, radiographic, and neuroimaging. Across time, practice has been debated and changed, based on ethical and legal issues; for example, making end-of-life and surgical decisions for a child with severe intellectual and physical disabilities. It is essen-

tial that research funding in this field is prioritized [32].

Governmental Influences

Over time, federal influences on the care of people with IDD have been both positive and negative and have arisen through public laws, legislation, and court cases. Highlights of each category will be discussed. For a full discussion of notable federal laws through 1999, see Nehring [5].

Public Laws and Legislation

As noted previously, early segregation of this population had not been for positive reasons; IQ testing and understanding of the etiology of IDD in the late 1800s and early 1900s influenced the eugenics movements and aided politicians to pass legislation to build institutions and asylums and to force women meeting certain criteria to be sterilized. First introduced in Indiana in 1907, sterilization laws aimed to decrease the incidence of IDD. These laws persisted for many years and were not erased until after the WWII (when the ultimate expression of the eugenics movement was revealed as one of the most egregious events in recorded history) in many instances, even after proof that they did not effect change was known. As a result of such acts of social injustice, human rights laws and regulations were passed beginning in the second half of the twentieth century [2, 3].

The Social Security Act of 1935 (P.L. 74–271) [85] ushered in the first of many positive legislative steps to assist people with IDD. This Act provided financial support to children with IDD, maternal and child health services, and child welfare services, among others [86]. Another significant piece of legislation was Section 504 of the Rehabilitation Act of 1973 (P.L. 93–112), which complemented the provisions in the Social Security Act [87]. These Acts and their revisions dictate Supplemental Security Income (SSI) benefits which many people with IDD receive. Consumers and their family members must remain diligent in their efforts to make sure needs are addressed as comprehensively as possible.

In 1992, the Americans with Disabilities Act of 1990 [88] was signed into law by President George H.W Bush. This Act is considered the largest civil rights bill since the 1960s and provided changes in discrimination, accommodations, employment, and architectural, communications, and transportational barriers [89].

The Patient Protection and Affordable Care Act (PL 111–148) [90] is the latest landmark legislation to address health and disparities. This Act covers discrimination, insurance, rehabilitation and habilitation services, accommodations, mental health, prevention and wellness, chronic disease management, and training for health professionals [91]. It is hopeful that the provisions in this Act will combat the barriers of access, quality, and cost.

Court Cases

Over the past several decades, the outcomes of many court cases have positively altered the lives of persons with IDD. A few of the most significant cases are discussed in this section.

Many educational laws, beginning with the Education of All Handicapped Children Act of 1975 (PL 94–142) [92] and the Education of the Handicapped Act Amendments of 1986 (PL 99–457) [93] and their subsequent amendments significantly changed the landscape for the education of children with IDD from birth through age 21 years and resulted from significant court cases (Pennsylvania Association for Retarded Children v. Commonwealth of Pennsylvania [94] and Mills v. Board of Education [95]). Although these laws were focused on education, opportunities to address health care needs were included as part of the services provided in many situations. As Individualized Education Plans or IEPs were introduced in the schools and Individualized Family Service Plans or IFSPs in early intervention programs, physicians and nurses were included as part of the team that assessed and reported on the children's progress [5, 96].

Wyatt v. Stickney (later changed to Wyatt v. Aderholt) [97] commenced in 1970 in Alabama and lasted 33 years and focused on the need for humane care for people with IDD and mental illness. As a result of this case, standards of care and habilitation needs were mandated and greatly influenced the deinstitutionalization movement [98].

Future Considerations

Across the years, many significant advances have resulted in our: (a) understanding and knowledge of IDD and prevalence and influences of secondary conditions; (b) need to revise terminology and classification systems; (c) need to make necessary changes in health care and its delivery, for all ages and ethnicities, and at all levels, including health promotion; (d) need to continue to prevent IDD; (e) need to increase the education of health care professionals; and (f) need to persist in identifying appropriate funding to conduct necessary research and include people with IDD as part of the research team. We still have far to go. In the coming years, the triple aims of quality, accessibility, and cost will remain priorities. Inequalities must continue to be discussed and altered [99]. A patient-centered medical home model for people with IDD and with availability of health professionals with expertise should be the norm.

The education of health professionals in the health care of people with IDD must be a priority. Education must be interdisciplinary, person-centered, culturally sensitive, comprehensive, across the lifespan, community-based, and occur at prelicensure and graduate levels [71, 99]. Until questions on IDD are included on licensing examinations for health professionals, a priority for inclusion in health professional education will not occur. If this is not accomplished, the future health care needs of people with IDD may not be adequately met [77].

Future research will focus on outcomes. National surveys, such as National Health Interview Survey, National Survey of Children with Special Health Care Needs, Behavioral Risk Factor Surveillance System, and The Medical Expenditure Panel Survey will continue to provide needed analytics and new and better questions should be added that provide essential information to plan optimal programs and services. The dissemination of these results must be coordinated with one federal agency [76, 100]. The National Center on Birth Defects and Developmental Disabilities at the Centers for Disease Control and Prevention [101] support health indicators to measure health and participation, health care and health promotion, associated and secondary conditions, and demographic variables. Krahn et al. [102] stressed the need for research in health promotion and health care access, which can be informed through better surveillance, measurement of quality of life, and involvement of people with IDD in research.

To better support future research efforts, people with IDD must be federally viewed as a disparity or underserved population and include a focus on access to quality health care [76].

Finally, politicians will need to consider all people as constituents and not discriminate in the provision of funding and services for people with IDD. Everyone, not just people with IDD and their family members and friends, need to advocate for needed care, education, and services across the lifespan and future legislation should be inclusive.

Summary

In this chapter, an abridged history of health care and impacting factors concerning people with IDD in the United States was discussed. Themes of terminology and classification systems, knowledge of IDD, health care delivery changes, education of health professionals, research, and federal influences were chronologically discussed. A final section on future considerations covered short- and long-term needs in these areas. The health status of people with IDD remains unequal to that of the general population. As this group of individuals continues to be integrated into the general population, it is hoped that greater opportunities for access, quality, and affordable costs will prevail. Health care is

dynamic and so are the possibilities for the future health care of people with IDD.

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