

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

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

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

Volume I

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 Springer

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**Part I**

**Introduction**



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## 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.

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David Satcher

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



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### 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.

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## 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].

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## 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].

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## **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.

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### **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

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## 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!

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