DOWN SYNDROME

VISIONS FOR THE 21ST CENTURY

EDITED BY

WILLIAM I. COHEN
Child Development Unit
Children's Hospital of Pittsburgh

LYNN NADEL
Department of Psychology
University of Arizona

MYRA E. MADNICK
National Down Syndrome Society

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The National Down Syndrome Society would like to dedicate this book to the real experts—the individuals with Down syndrome and their families who are in the forefront of the Down syndrome movement. Their insight, passion, and dedication have greatly enhanced the lives of all people with Down syndrome.

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PREFACE

Down Syndrome: Visions for the 21st Century grew out of the NDSS conference of the same name held July 27–29, 2000 in Washington, DC. A major goal of this conference was to create a dynamic vision for the new century by asking the more than 650 participants to share their ideas and priorities in education, research, and advocacy. This book encompasses that theme and the mission of NDSS: to ensure that all individuals with Down syndrome are provided the opportunity to achieve their potential in community life.

Visions is designed to explore the highlights of the conference through chapters submitted by many of the presenters. This book will be most valuable to several different groups of people including parents and family members of individuals with Down syndrome, expectant parents of children with Down syndrome, educators, physicians, and health care professionals as well as the interested public.

The book is divided into ten sections that include specific chapters on topics of interest to both parents and professionals. The first three sections, Self-Determination, Self-Advocacy, and Advocacy, address the issues of how individuals with Down syndrome and their families can play a greater role in how the person with Down syndrome optimally leads his/her life. This material is augmented by a number of accounts written by young adults with Down syndrome.

The next section, Role of the Family, includes personal reflections by parents of children with Down syndrome as well as chapters on siblings and life planning. The following section, Health and Clinical Care, is comprehensive, covering such topics as pediatrics, gross motor development, behavior, adult health care, and the recently updated Healthcare Guidelines for Individuals with Down Syndrome (1999).

The Research section includes in-depth discussions of the sequencing of chromosome 21, alternative therapies, and recent advances in research. Psycho-Social Issues are the theme of the next section, which includes chapters on relationships, sexuality, healthy lifestyles, and autism and Down syndrome.

One of the most important topics for people with Down syndrome, their families, and professionals is addressed in the Education/Inclusion section. Such topics as the philosophy of inclusion, positive behavioral supports, postsecondary education, and assistive technology and computers are discussed. Another aspect of education is detailed in the Communication, Math, and Language Skills section. This section includes discussions of speech and language for infants, toddlers, children, and adolescents as well as the teaching of reading and math to children with Down syndrome.

The book concludes with a section entitled Turning the Vision into Reality, which examines the significant changes that have occurred for people with Down syndrome and the many challenges that lay ahead.

This book will assist the reader in obtaining a better grasp of the present and an understanding of what the future could hold for individuals with Down syndrome if we work collectively to make positive changes across all disciplines.

William I. Cohen, M.D.
Lynn Nadel, Ph.D.
Myra E. Madnick, M.Ed.

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CONTRIBUTORS

GILLIAN BARLOW, PH.D.
Cedars-Sinai Medical Center

MARTHA BECK, PH.D.
Phoenix, AZ

PRANAY BHATTACHARYYA, B.S.
Cedars-Sinai Medical Center

CHRIS BURKE
National Down Syndrome Society,
New York, NY

GEORGE T. CAPONE, M.D.
Department of Pediatrics, Johns
Hopkins University School of
Medicine, Baltimore, MD, and
Division of Neurology and
Developmental Medicine, Kennedy
Krieger Institute, Baltimore, MD

XIAO-NING CHEN, M.D.
Associate Professor of
Pediatrics, UCLA
UCLA School of Medicine
Cedars-Sinai Medical Center

BRIAN A. CHICOINE, M.D.
Adult Down Syndrome Center of
Lutheran General Hospital,
Park Ridge, IL

WILLIAM I. COHEN, M.D.
Down Syndrome Center,
Children's Hospital of Pittsburgh,
Pittsburgh, PA

W. CARL COOLEY, M.D.
Department of Pediatrics,
Dartmouth Medical School,
Hanover, NH, and Crotched
Mountain Rehabilitation Center,
Greenfield, NH

HANK EDMONSON, M.ED.
Loyola University, Chicago, IL

TERRY HASSOLD, PH.D.
Department of Genetics and The
Center for Human Genetics, Case
Western Reserve University and
The University Hospitals of
Cleveland, Cleveland, OH

JOHN PETER ILLARRAMENDI
Bethesda, MD

PHYLLIS JACKS, ED.D.
Chapel Haven, New Haven, CT

Julie R. Korenberg, Ph.D., M.D.
Professor of Pediatrics & Human Genetics, UCLA
Brawerman Chair of Molecular Genetics, Vice Chair for Pediatrics, Research Cedars-Sinai Medical Center

Libby Kumin, Ph.D., CCC-SLP
Speech-Language Pathology Audiology Department, Loyola College in Maryland, Graduate Center, Columbia, MD

Andrea Lack, M.S.W., C.S.W.
National Down Syndrome Society, New York, NY

Len Leshin, M.D., FAAP
Corpus Christi, TX

Susan P. Levine, M.A., C.S.W.
FRA, Shrewsbury, NJ

Gary E. Lyons, Ph.D.
Associate Professor, Anatomy/Pediatrics, University of Wisconsin Medical School, Madison, WI

Jeffery Mattson
Monarch Beach, CA

Kathleen H. McGinley, Ph.D.
Health Care and Housing Policy, The Arc of the United States, Washington, DC

Dennis E. McGuire, Ph.D.
Adult Down Syndrome Center of Lutheran General Hospital, Park Ridge, IL

Joan E. Medlen, R.D., L.D.
Disability Solutions
Portland, OR

Michael Morris
Community Options, Inc., Washington, DC

Thomas Nerney
Center for Self Determination, Ann Arbor, MI

Joshua G. O'Neill
Fort Wayne, IN

Thomas J. O'Neill
Admetco, Fort Wayne, IN

Patricia Logan Oelwein, M.Ed.
Bellevue, WA

Bonnie Patterson, M.D.
Cincinnati Center For Developmental Disorders, University of Cincinnati, Cincinnati, OH

David Patterson, Ph.D.
The Eleanor Roosevelt Institute, Denver, CO

Mia Peterson
National Down Syndrome Society, Cincinnati, OH

Siegfried M. Pueschel, M.D., Ph.D., J.D., M.P.H.
Child Development Center, Rhode Island Hospital, Providence, RI

Lora S. Salandanan, B.S.
Cedars-Sinai Medical Center

Stephanie Sherman
Department of Genetics, Emory University School of Medicine, Atlanta, GA

Stephanie Smith Lee
National Down Syndrome Society, Oakton, VA

JACQUELINE THOUSAND, PH.D.
College of Education, California State University, San Marcos,
San Marcos, CA

ANN TORNBILL, ED.D.
University of Kansas,
Lawrence, KS

RICHARD A. VILLA, ED.D.
Bayridge Consortium, Inc.
San Marcos, CA

LESLIE WALKER-HIRSCH, M.ED.
Moonstone Group, Yorktown Heights, NY

JOSEPH F. WALLACE, PH.D.
Virginia Assistive Technology System, Richmond, VA

DAVID A. WEINGARTEN
Wealth Advisory Group LLC,
New York, NY

PATRICIA C. WINDERS, PT
North East, MD

PART

I

SELF-DETERMINATION

CHAPTER

1

UNDERSTANDING SELF-DETERMINATION

THOMAS NERNEY

INTRODUCTION

The new century offers the possibility of unparalleled opportunities for individuals with Down syndrome. It offers as well the hazard of rising skepticism concerning the value of individuals with cognitive and intellectual disabilities.

The enormous gains made in the last third of the twentieth century in education, employment, and community living for these individuals can be further broadened. For this to occur, society must change the terms and rationale for obtaining necessary supports to those based on freedom and equality rather than paternalism and professional domination. As well, support for long-term care will falter without a better grounding in public policy, law, and ethics that is more widely shared by the larger society.

Individuals with Down syndrome today are benefiting from so much that has been learned from the fields of medicine, education, and rehabilitation that it would not be too optimistic to predict further gains if structural reforms of the present human service system are implemented quickly and carefully. These reforms would place the authority for controlling individual budgets needed for support with the individual, family, and close allies. Information and data garnered to date from the self-determination movement demonstrate the cost-effectiveness of this approach and the improvements in quality.

However, the backlash occurring throughout this country over special education spending seems likely to move into the field of long-term care sooner rather than later. The strain on state Medicaid budgets will be exacerbated as America ages and the population over 65, and especially over 85, increases dramatically. A new utilitarian agenda arising from the field of bioethics is beginning to call into question the value of any public expenditure that purports to serve those who cannot "benefit"—those with cognitive and intellectual disabilities (Nerney, 1999). This recent assault on the value of individuals with intellectual disabilities can be traced to Drs. Duff and Campbell, who wrote one of the first articles to be published in the *New England Journal of Medicine*. In 1973 they revealed that they did not treat many babies born with disabilities at Yale New Haven Hospital (Duff and Campbell, 1973). These decisions were based on "quality of life" criteria. Life-long disability was now a subject for debate.

But the debate soon moved from quality of life considerations to considerations regarding the cost to society. A group of doctors and social workers published a seminal article in *Pediatrics*, the journal of the American Academy of Pediatrics, in 1983 explaining that they made decisions not to treat infants born with spina bifida based on both quality of life criteria and the resources available to families as well as from society (Gross et al., 1983). Contemporary discussions in the bioethical literature point out the lack of "benefit" for providing needed supports to individuals with cognitive disabilities (Buchanan and Brock, 1992; Walker et al., 1984; Hardwig, 1997). Individuals with cognitive or intellectual disabilities are no longer seen, according to this literature, as worthy of society's resources. The Australian ethicist Peter Singer has been calling into question the value of individuals with Down syndrome since 1979 (Singer, 1979; 1984; 1991; 2000). Long considered by many to be outside the mainstream of contemporary philosophy, Singer was recently appointed to an endowed chair at Princeton University.

This tension, then, will mark the early decades of the twenty-first century. Our response to it may very well determine whether continued commitment to individuals with these disabilities receives widespread support from elected and appointed officials as well as ordinary citizens across the country.

BACKGROUND

In the early 1990s a small group of people in southeastern New Hampshire asked the following question: "What would the human service system for individuals with cognitive disabilities look like, how would it perform, if those with disabilities, their families and allies controlled the resources?" This fundamental attempt to both question the foundation for the current system and suggest a fundamental realignment of power and control arose from a systematic evaluation of policies and practices in what was arguably one of the finest systems in the United States. Visitors from across the country and from other lands came to Monadnock Developmental Services to observe. Group homes averaged fewer than three individuals. Everyone lived in the community. New Hampshire was touted for its efforts in supported employment. Nonetheless, this small group raised serious questions about just how far off the rhetoric of human services was from the reality of those being served.

People with disabilities were far from fully participating members of their communities. Few had any say about where or even with whom they would live. Average wages and hours in supported employment were close to negligible. Individual service plans focused on goals and activities not germane to a meaningful life in the community. Many individuals merely remained "supervised" during the day. Few had keys to their homes or ready access to transportation. In fact, some individuals were not safe. The current system had unintentionally relegated them to second-class citizenship.

On the basis of these analyses and the initial experience of what was later to be called "self-determination," the first monograph was produced calling for a fundamental overhaul in the system. Entitled "An Affirmation of Community: A Revolution of Vision and Goals" (Nerney and Crowley, 1993), it systematically laid out the vision necessary to meet the rhetorical goals of real community inclusion, real choice and freedom, and meaningful membership in one's community. The publication of this document was meant to articulate for all community members that individuals with disabilities in southeastern New Hampshire had a right to fully participate in society, not as clients of a human service system, but as ordinary citizens with the supports in place to help them accomplish these and other highly personal goals.

THE "EXPERIMENT"

A demonstration involving 45 persons with disabilities, including those with very significant disabilities, was launched in 1993 with the assistance of a grant from the Robert Wood Johnson Foundation. In that grant request the authors stated that the present human service system was so ". . . outmoded, so disenfranchising and so costly that radical departures must be demonstrated and evaluated immediately." The simple premise was that as individuals and their allies gained control of the resources, quality would improve and costs would be better managed (Conroy, 1996).

Patty, a young lady with Down syndrome, was one of the early participants. Patty had an extraordinary personal relationship with two direct support workers who were about to be married. All three joined forces to buy a house together and create a new life in their community. Patty became involved with a town softball league as assistant manager and today lives in a home she now owns.

Sean lay in a coma for five years in a hospital and nursing home in a nearby state as a result of an acquired brain injury that occurred in high school. The professionals had given up on him after that length of time. His mom and dad wanted to bring him back to his home community. With fewer resources than the nursing home used for custodial care, Sean moved into his own home with support staff hired by his family and a budget developed by them. Sean's improvements have been slow but very noticeable. Today he frequently accompanies his parents on the lecture circuit.

Julie was in the last stages of a degenerative disease. She had no family involvement but did have some committed friends who all worked in the human service system. Her dream, they all knew from the years when she used speech, had been to move out of the group home and into her own place with staff who had exhibited real interest and love for Julie. With her individual budget completed, Julie moved to her own place and lives there today in defiance of her prognosis.

Cathy was a woman with very significant disabilities who was continually found to be unsafe in a variety of community placements. There was evidence of abuse. By researching her records and speaking carefully with family and others, it was discovered that she and her twin sister, who lived in another state, had long ago dreamed of living together. Typical human service systems neither recognized nor supported these arrangements. Soon, Cathy with her case manager got into a car and drove to a nearby state to the home of her sister. Funds from her budget had been used to make the house accessible, and her budget just happened to be enough to cover the lost salary her sister would experience from leaving her job as a nurse.

Individuals began to think of what has now become the hallmark of self-determination: looking at public dollars as an investment in the lives of individuals with disabilities. One-time investments and small, creative purchases were tried as well.

Ron was a middle-aged man who always wanted to get a job. Agencies had been paid for years to accomplish this task. One day a commitment of $500 was put on the table for *anyone* who could get Ron a job he liked. A few weeks later, a staff member from his group home came in to collect. Ron then demonstrated the power of small, creative purchases. He used $200 from his budget to help a local experimental theatre group rent space to practice. Ron became a member and today lives in a life-sharing arrangement with another member of the troupe.

Rethinking current expenditures, addressing system change issues, and listening more deeply to individuals with disabilities, family members, and close allies (including direct support staff) from both the human service system and the wider community became a new way of doing business. At the end of two years, the results were startling. Change was so positive that it was palpable and measurable. It was measured independently by a Robert Wood Johnson Foundation contract (Conroy, 1996). The costs for a few individuals went up because they had been so poorly served in the past. Many remained the same. Some decreased considerably. At the end of the "experiment" the annualized savings in this resource rich state amounted to $300,000.

This was an unusual experiment. For the first time individuals with disabilities were not asked to change. The "experiment" was on those who managed and worked in human services to see if *they* could change. The essential goal of self-determination had become clear. It was to change the human service system from one in which individuals gave up their freedom in favor of professionally directed services to one in which individuals could craft a meaningful and unique life deeply embedded in their communities.

NATIONAL INITIATIVE

The Robert Wood Johnson Foundation then moved to set up a national program office at the University of New Hampshire and sent out a request for proposals (RFP) to increase the number of demonstration sites across the country. Five million dollars was made available for this effort. Thirty-five states and the District of Columbia responded—one of the largest state responses to an RFP in the history of the Foundation.

Nineteen states received grants ranging from $100,000 to $400,000. The following year another, smaller technical assistance fund allocated dollars to an additional 10 states. Interest in self-determination spread rapidly throughout the country and has been featured in countless meetings, trainings, and national and international self-determination conferences. In 1996 self-determination was articulated as a series of principles to give greater clarity to the demonstration sites and to keep the original vision alive:

> *Freedom:* the ability for persons with a disability to choose where to live and with whom as well as to choose what important activities would be features of their lives.
>
> *Authority*: the ability of a person with a disability to control necessary and sufficient resources with the assistance of valued friends, family, and allies. This would be accomplished with the development of a highly unique individual budget with the assistance of a fiscal intermediary to handle disbursement and tax and benefit issues.
>
> *Support*: the creation of highly personal and unique support plans that reflected the dreams and ambitions of the person with a disability.

> *Responsibility*: the mandate for the wise use of public dollars and for the ability of each person with a disability to contribute to the community (Nerney and Shumway, 1996).

Following the advice and input of the national self-advocacy organization SABE, the Center for Self-Determination added the following fifth principle in 2000:

> *Confirmation*: recognition of the major role that individuals with disabilities must play in the redesign of the human service system and recognition of the importance of supporting the self-advocacy movement.

EXPERIENCE OVER FIVE YEARS OF DEMONSTRATIONS

The demonstrations and pilots carried out in the ensuing five years ranged from small, local or county-based ones to statewide reform efforts. Some abandoned the goals of the initiative early on, all struggled with complex system issues, and, with small successes in a variety of urban and rural areas, some committed to real change in their systems to make self-determination a reality for all those served. These latter projects realized that this kind of system and cultural change would require many years to implement. Self-determination is an ongoing proposition in demonstrations large and small in over 30 states today.

Two relatively innovative assumptions began to undergird the self-determination movement for all individuals with disabilities. One is that all persons should "have their own place," and, two, that virtually all individuals can work in meaningful employment and/or produce income through the development of microenterprises. Individuals with disabilities may indeed want to live with another person, but that is always a freely chosen situation and one susceptible to renegotiation when necessary. More and more projects across the country are gradually changing the goal from "getting a job" to one of "producing income." This enables everyone to understand that there are many ways to secure employment or to start a very small business. In the future, if reform is to be successful, individuals within their budgets may (with assistance from a variety of sources) contract directly with employers for coworker support, transportation, and even training. Individual budgets then may also be used to help secure or pay down the cost of equipment necessary for a microenterprise (Nerney, 1998).

To accomplish the system changes necessary for successful self-determination, the following minimum structural changes must be implemented:

Individual Budgets

Based on current best practice, individual budgets meet *ideal* requirements for self-determination when the budget is actually controlled by the person and their freely chosen allies. Public dollars are now seen as an ongoing investment in the person's life, and the obligation to be responsible as well as to contribute to one's community becomes part of the budget development. In many demonstrations these ideal standards are only partially reached, but this represents an important step in the right direction. This means that the following is in place:

Individually Created Budgets

The person with a disability and freely chosen family and friends create individual budgets. This includes the creation of unique line items that reflect the distinct dreams and ambitions of the person with a disability.

Authority over Personnel

Any person who works for the individual with a disability is hired and can be fired as well by that person with assistance when necessary. In fact, all employees and consultants work for the person and that person's social support network. Even if another organization assumes some legal responsibility, to become the employer of record, for example, all personnel and consultants work for the person with a disability.

Flexibility

Within approved amounts, dollars can be reasonably moved from line item to line item as long as the essential supports are maintained. New line items may also be created as well as old ones being erased.

Independent Support Coordination

The linchpin to the success of creative, highly individual budgets and life plans is the function that is variously referred to as independent support coordination, "personal agents," or independent brokering. What is important with regard to this function is the potential for conflict of interest. This is a person who may help with plan development, assist in organizing the unique resources that a person needs, and even assist with ongoing evaluation of these supports. There are many ways that this function can be carried out, from family members doing it to case managers assuming new roles. In today's complex case management-dominated systems, there must be a retraining of case managers and, frequently, the addition of an independent broker as well. These brokers can be individuals who operate as independent contractors or an agency that specializes in providing only these kinds of individual supports. Ideally, individuals with disabilities and family members can govern these agencies. One creative project allows the person with a disability to select anyone they know and trust and to pay them separately if necessary. When ongoing and independent support coordination is also required, some individuals are including this cost in their individual budget because it can meet the test of a "service." The characteristics of an independent brokering function include the following.

INDEPENDENCE FROM SERVICE PROVISION

It is important to keep this function separate from any form of service provision to avoid both the appearance and the reality of conflict of interest. Even those "brokers" who have great integrity should not be put in a position of divided loyalties. Current systems, which feature service provision and support coordination, may take years to accomplish the transition. Many individuals with disabilities and families have relationships and loyalties in place that must be respected while this transition proceeds.

REAL AUTHORITY

Whether the person is an independent contractor or works for an independent agency, this function has to carry some state, county, or publicly sanctioned authority if he/she is to adequately represent the person with a disability. Again, it should be clear that the person who carries out this function works for the person with a disability.

FISCAL INTERMEDIARIES

Fiscal intermediaries are simply organizations, places, really, where an individual budget gets "parked" or "banked." The functions carried out by a fiscal intermediary include, but are not limited to, check writing for all bills and personnel costs, tax withholding, and paying worker's compensation, health insurance, and other taxes and benefits that might be appropriate depending on the individual's budget. The fiscal intermediary works for the individual and remains accountable for ensuring compliance with all federal and state laws. In some localities, community banks are carrying out this function. New organizations are also springing up to provide this service. State-imposed Medicaid regulations frequently dictate which organizations or individuals can carry out this service. Minimum standards include the following.