

# THROUGH THE MAZE

A Guide to Health Care &  
Insurance Rights & Resources  
for Californians with Disabilities



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Insurance Rights & Resources  
for Californians with Disabilities

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# Preface

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Access to health care and insurance is the difference between living a quality life, existing day-to-day, or dying.

In the spring of 1999, I woke up one morning, opened my eyes, and came to the realization that I was dying. The lack of accessible medical facilities, medical equipment, and comprehensive quality health care, along with assumptions about my disability based on my weight, had placed me in the position that if I did not get proper medical attention soon, I would die within six months.

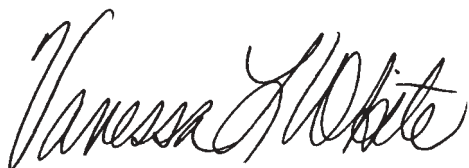
The first thing I had to do was accept that access to health care is a basic right for all people, including people with disabilities. Unfortunately, the health care industry and the disability rights movement have been at odds for a long time. The lack of understanding between these two has helped to create and maintain service delivery systems that, at best, provide less than adequate health care to people with disabilities. Several factors help perpetuate this problem. Traditionally, doctors have not been trained to provide comprehensive and quality health care to the disability community. Instead, the medical system has emphasized cures for health conditions. As a result, it has ignored the needs of men and women with disabilities who are not seeking to cure their conditions, but to live with their disabilities. The medical system is also often paternalistic in its approach to our health care. Instead of creating a partnership with us, medical providers frequently make decisions about our care without our input. In many cases, they talk to our family or our caregivers instead of us. It sometimes appears that they think we do not have the capacity to understand our own health conditions. Our repeated experience of inaccessible and inadequate health care has rendered us mistrustful of and disengaged from the medical system. All too often, we have accepted such conditions through indifference, fear, anger, and apathy. The challenge that faces people with disabilities is to take back our power—require that our health care and insurance providers enter into new partnerships with us to better manage our health care and insurance needs.

At first, being my own advocate was very hard for me. I had allowed the health care system to make all the decisions for me concerning the treatment of my disability, to the point where I had become immobilized. I finally realized that I had to take personal responsibility for my health and begin to advocate for my health care.

For me, the key to self-advocacy was making the decision to live a quality life—not just to exist. My first step was to establish a strong support network, which included my family, friends, a disability service agency, and my doctor. Since my doctor and I agreed to establish a partnership, he has become my greatest advocate in a medical system that is immersed in red tape. I now understand that we can no longer leave our health care to the HMOs and other insurers. Two years later and four hundred pounds lighter, I can truly say that I am living a quality life and that I have never before felt such a sense of happiness and well-being.

The bureaucracy of the health care and insurance industries can be daunting and confusing, but knowledge is power. This publication was written to educate people about their rights and how to exercise them. *Through the Maze* is a comprehensive look at the issue of access to health care and insurance. This publication addresses many types of barriers, including physical, communication, and attitudinal barriers. It covers access to private health insurance and public health programs. It provides many resources to guide both consumers and their providers through the health care and insurance maze. It is the hope of Disability Rights Advocates that this handbook will enable consumers, advocates, health care providers, and the health care and insurance industries to work together to provide quality health care and insurance for all our citizens.

Be Well,

A handwritten signature in black ink that reads "Vanessa L. White". The signature is written in a cursive, flowing style.

Vanessa L. White, Director  
Health Access Project

# Introduction

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Getting good health care is a challenge for many people with disabilities. Sometimes the problem is a physical barrier, such as a steep ramp or an examination table that is too high. Other times, a lack of interpreters or alternative formats such as Braille causes ineffective communication between the patient and the health care provider. And sometimes a health care provider's poor understanding or bad attitude about disability gets in the way. Because of these and other types of barriers, going to the doctor can be an uphill struggle. High health care costs and problems with insurance make the problems worse and lead many people with disabilities to go without the health services they need.

By introducing you to federal and state laws that protect Californians with disabilities, this handbook can help. When you know your rights, you can be a better advocate for yourself and your family.

The handbook has three main sections:

## **Section 1: Access to Health Care**

Section 1 explains your right of access to health care facilities and the services they provide. It also discusses your right to emergency care and includes tips for choosing a provider and handling access problems.

## **Section 2: Private Insurance**

Section 2 helps you learn about insurance rights in California, including: (1) protections when you get health insurance through a job or apply on your own, (2) benefits that health plans must include, (3) access to primary care doctors, specialists, and second opinions, (4) challenging an insurer's refusal to pay for your care, and (5) continuing your coverage when you lose access to an employer's group health plan. This section also introduces you to long-term care insurance and Medigap insurance, which supplements Medicare.

## **Section 3: Public Health Programs**

Section 3 discusses programs that offer free or low-cost insurance or health services in California. It includes information about durable medical equipment (DME), the relationship between immigration status and public health benefits, and transportation.

This handbook is a resource you can keep and turn to when you have questions about access to health care, insurance, or public health benefits in California.

Because the information presented here can be complicated, do not be surprised if you need to read some sections more than once. Quotation marks are often used for special terms, many of which are defined in the text. When a deadline for taking action is noted, assume that the clock starts ticking on the date that is on the notice of the decision you want to challenge (not the date you receive the notice). Because many topics relate to one another, you will often see references to other handbook pages. The table of contents and index can also help you find the topics that matter to you.

The following icons appear next to paragraphs containing telephone numbers, websites, deadlines, and other key information.



Very Important!



Good to Know



Deadline



Telephone Number



Website/  
E-mail

This handbook does not tell you all there is to know about the law, and it is not legal advice for your individual situation. The laws governing health care and insurance are complex and frequently change. (Check DRA's website for updates on the law.) It is important that you get accurate and up-to-date information if you encounter a problem or need to make a decision about your health care, insurance, or public health benefits. Sometimes, you may need a lawyer or other advocate. The handbook identifies sources of information and help. Many resources are listed in the text, where they relate to the topic being discussed. More general disability and health resources are included in the Resource Guide that starts on page 147.



This guide comes in alternative formats (Braille, large print, and computer disk) and in Spanish, and it is available online at [www.dralegal.org](http://www.dralegal.org). It is part of the Health Access Project at Disability Rights Advocates (DRA), a nonprofit law center dedicated to protecting the civil rights of people with disabilities. DRA conducts workshops about health care and insurance rights. In addition to this handbook, DRA has other publications, including *Disability Watch, Volume 2* (a statistical report about people with disabilities) and a legal treatise on health care and insurance rights for people with disabilities. The legal treatise is a more technical version of this handbook.



To order a free handbook or check if a workshop is scheduled for your area, call DRA at: 888-926-0274 (toll-free), 510-451-8644 (voice), 510-451-8716 (TTY), or e-mail [healthaccess@dralegal.org](mailto:healthaccess@dralegal.org).



[healthaccess@dralegal.org](mailto:healthaccess@dralegal.org).

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# Table of Contents

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WHAT IS THE HEALTH ACCESS PROJECT AT DRA? . . . . .	(inside front cover)
PREFACE . . . . .	iii
INTRODUCTION . . . . .	v

## Section 1: Access to Health Care

SECTION HIGHLIGHTS . . . . .	2
INTRODUCTION TO ACCESS RIGHTS . . . . .	3
Who must provide access • Your right to auxiliary aids and services • Dealing with negative attitudes about disability • The laws that promise access • Program access • No segregation in an institution when community-based care is more appropriate	
PHYSICAL ACCESS . . . . .	7
Barrier-free medical buildings • Standards for architectural access • Accessible medical equipment and health procedures •	
COMMUNICATION ACCESS . . . . .	9
Improving communication • Passing notes, reading lips, and relying on interpreters • Telecommunication devices (TDDs/TTYs) • Captioning and assistive listening devices	
SERVICE ANIMALS . . . . .	12
ACCESS FOR PEOPLE WITH MULTIPLE CHEMICAL SENSITIVITY OR ENVIRONMENTAL ILLNESS . . . . .	12
YOUR RIGHT TO EMERGENCY CARE . . . . .	13
Emergency medical conditions • Stabilizing your condition • Transfers • Paying for emergency care	
GETTING QUALITY, ACCESSIBLE HEALTH CARE . . . . .	14
Choosing a health care provider • Informed consent • Getting to your appointment • The appointment • Preparing for a hospital visit • Advance directives • Rights for nursing home and long-term care facility residents • Tips to help you be your own advocate • Filing a lawsuit to enforce your access rights • Getting help with an access problem	

**Section 2: Private Insurance**

SECTION HIGHLIGHTS . . . . . 22

**PART I: HEALTH INSURANCE**

CHOOSING YOUR HEALTH INSURANCE . . . . . 23

    Types of plans • Plan costs • Medical groups • Getting “medically necessary” care • Information the plan must give you • Reading your plan information carefully • Disability-based insurance discrimination

GETTING HEALTH INSURANCE THROUGH YOUR JOB OR A FAMILY MEMBER'S JOB . . . . . 27

    Protection from group plan discrimination • Waiting and affiliation periods • Self-insured (or “self-funded”) group plans • Enrolling in a group health plan

GETTING HEALTH INSURANCE ON YOUR OWN . . . . . 29

    The health insurance application • Guaranteed access to an individual health plan

MAJOR RISK MEDICAL INSURANCE PROGRAM (MRMIP) . . . . . 32

HELP FOR THOSE WHO GET SICK AND CAN NO LONGER AFFORD THEIR PREMIUMS (HIPP AND CARE/HIPP) . . . . . 33

YOUR RIGHT TO CONTINUE YOUR HEALTH PLAN . . . . . 34

PRE-EXISTING CONDITIONS . . . . . 35

    How long a pre-existing condition exclusion can apply • How the law helps • Shortening the pre-existing condition exclusion with creditable coverage • When a pre-existing condition exclusion cannot apply

BENEFITS YOUR HEALTH PLAN MUST INCLUDE . . . . . 38

ACCESS TO HEALTH CARE PROVIDERS . . . . . 41

    Picking and working with a primary care doctor • Direct access to a gynecologist or obstetrician without a referral • Access to specialists • Standing referrals for specialists • Access to an AIDS/HIV specialist • Access to a specialist who is not part of your plan • Your rights when your plan terminates your provider • Continuing treatment with a provider who is not part of your new group plan • Getting a second opinion • You cannot be singled out for reduced care

MAKING CLAIMS FOR HEALTH BENEFITS AND CHALLENGING COVERAGE DENIALS . . . . . 45

    Which laws protect you • Claim reviews, appeals, and lawsuits under federal law (ERISA) • Claim reviews, grievances, independent medical reviews, and lawsuits under California law • Tips for challenging a health plan’s coverage denial

HELP WITH A HEALTH INSURANCE PROBLEM . . . . . 57

MAINTAINING HEALTH COVERAGE WHILE ON LEAVE FROM WORK . . . . .	58
KEEPING HEALTH COVERAGE WHEN YOU ARE LOSING EMPLOYER-PROVIDED INSURANCE (COBRA/CAL-COBRA) . . . . .	59
SENIOR COBRA . . . . .	65
KEEPING HEALTH INSURANCE FOR A CHILD WITH A DISABILITY . . . . .	66
CONTINUING BENEFITS IF THE GROUP PLAN CONTRACT ENDS WHILE YOU ARE TOTALLY DISABLED . . . . .	67
CONVERTING FROM A GROUP PLAN TO AN INDIVIDUAL PLAN . . . . .	69
<b>PART II: MEDIGAP (MEDICARE SUPPLEMENTAL) INSURANCE</b>	
FILLING GAPS IN MEDICARE COVERAGE . . . . .	69
<ul style="list-style-type: none"> <li>The 10 standard Medigap plans • Benefits • Medicare Select • Exclusions for pre-existing conditions • When you have a right to buy Medigap insurance • Group vs. individual Medigap insurance and your right to renew • Reasons why some Medicare beneficiaries may not need Medigap insurance • Whether to get Medigap insurance</li> </ul>	
<b>PART III: LONG-TERM CARE INSURANCE</b>	
INSURANCE FOR PERSONAL CARE . . . . .	77
<b>Section 3: Public Health Programs</b>	
SECTION HIGHLIGHTS . . . . .	82
MEDICARE . . . . .	83
<ul style="list-style-type: none"> <li>Help with Medicare costs • What is not covered • Signing up for Medicare • If you qualify for Medicare but have other insurance options • Part A • Part B • Providers who do not accept Medicare • Medicare+Choice (Part C) and Medicare HMOs • Claim reviews, appeals, and your right to a hearing • Federally qualified health centers • More information and help with Medicare • Keeping Medicare as you transition back to work</li> </ul>	
PRESCRIPTION DRUG DISCOUNT PROGRAM . . . . .	97
PACE (PROGRAMS OF ALL-INCLUSIVE CARE FOR THE ELDERLY) . . . . .	97
MEDI-CAL . . . . .	98
<ul style="list-style-type: none"> <li>Medi-Cal services • Medi-Cal costs • Eligibility • Different Medi-Cal programs • Applying for Medi-Cal • Fee-for-service vs. managed care • Appeals and the right to continue benefits during the appeal</li> </ul>	
COUNTY MENTAL HEALTH PLANS . . . . .	112

PROGRAMS FOR PEOPLE WITH DISABILITIES . . . . .	114
<p>In-Home Supportive Services (IHSS) • Genetically Handicapped Persons Program • Regional Centers • Early Start • California Department of Rehabilitation and the Client Assistance Program • Projects for Assistance in Transition from Homelessness • AIDS Drug Assistance Program • CARE/HIPP</p>	
PROGRAMS FOR CHILDREN . . . . .	119
<p>Healthy Families Program • California Children Services • HIV Children's Program • CaliforniaKids • Kaiser Permanente Cares for Kids Child Health Plan • Local School Districts</p>	
PROGRAMS FOR PREGNANT WOMEN, NEW MOTHERS, AND THEIR YOUNG CHILDREN . . .	124
<p>Access for Infants and Mothers (AIM) • Women, Infants, and Children (WIC) • BabyCal</p>	
OTHER HEALTH CARE RESOURCES . . . . .	125
<p>Health Care Clinics • County Medical Services Program • Breast Cancer Early Detection Program • California Department of Aging • Veterans Health Administration</p>	
DURABLE MEDICAL EQUIPMENT (DME) AND ASSISTIVE TECHNOLOGY (AT) . . . . .	127
PUBLIC HEALTH BENEFITS AVAILABLE FOR IMMIGRANTS . . . . .	129
FINDING AND PAYING FOR TRANSPORTATION . . . . .	132
<b>Appendices</b>	
WORKING WITH A LAWYER . . . . .	135
INDEX . . . . .	137
RESOURCE GUIDE . . . . .	147
ACKNOWLEDGMENTS . . . . .	<i>(inside back cover)</i>