



Council on Mental Retardation  
Leadership Institute  
101 Witherspoon Street  
Louisville, KY 40202

Phone 502 587 6500  
Fax 502 587 6570  
www.councilonmr.org

---

# Introduction

---

## Guidelines and Resources for Getting the Life You Want

### How and When to Read These Guidelines

These Guidelines cover topics and issues that may occur and be of significance over the span of a **young adult's** life, particularly from **ages 16 to 26, and many pieces of the information may apply on into maturity.** Each section is intended to give information to consumers and families at a time when those topics are most important and is to be read at that time. **Warning to parent and caregivers, you probably will not and perhaps should not read the entire Guidelines at one time,** even if you are compulsive enough to want to try. It will be overwhelming. The task of helping a loved one establish a meaningful life may seem overwhelming when you look at the whole, but as with every aspect of life, we can only handle one day at a time. When you use this manual, **look at the tabs or the Table of Contents and read the section you need when you need it.**

There may be days when just *getting through the day* seems impossible, but believe that it will be worth it! The biggest adjustment is to realize that no services are guaranteed to an adult with disabilities. Therefore, as a consumer, parent or caregiver, it is necessary to be proactive and plan ahead.

### About These Guidelines

These Guidelines are intended to help consumers and their families access and navigate Kentucky's Developmental Disabilities Service System. **A major section was written specifically to explain Medicaid Managed Care Health Plans with an emphasis on important Health Promotion Practices.** We hope this inclusion will encourage direct support professionals to develop skills related to supporting the health and well being of persons with developmental disabilities.

*One generation plants the tree; 1 another gets the shade . . .*

Over and above this purpose, we felt the need to help persons with disabilities and their families learn about other components of a full life. Therefore, we added sections on issues that revolve around transition and planning for services, as well as a discussion of the principles of self-determination and freedom of choice. These principles are essential in selecting supports and services that meet individual needs. An explanation of funding sources, especially governmental programs through Medicaid and other sources also are of great concern to families. So the Guidelines grew and grew and eventually became a “living organism” that will be constantly changing through additions and corrections in print and on a website.

Although much of the general information is applicable to consumers across the Commonwealth, some of the specific resource material applies only to people living in the Louisville Metro area and surrounding counties.

**Special Note:** Change is inevitable; therefore, the printed copy of the “Guidelines and Resources” may include some information that is dated. For the most current copy of the material, please see the website of the Council on Mental Retardation, [www.councilonmr.org](http://www.councilonmr.org). In addition, periodic updates of the information will be available in CD format. Call the CMR Leadership Institute at 587-6500 for additional information about revisions.

## **The Purpose of these Guidelines**

Before someone sets out on any journey, he or she needs a map or a plan, some way to get there, to navigate. As a person with disabilities, **finding a path in life as an adult and getting the life you want are the most important goals you will ever work toward.** The purpose of these Guidelines is to give you and your parents/caregivers the information you need to plan ahead, see what your choices are, assist you in making decisions, and help you overcome obstacles in your way. The Guidelines are written in a clear, down-to-earth manner to help you learn what services and supports are out there and also how to put the pieces of the service system together so that you, the consumer, with the help of your parents and/or circle of support, can get the life you want.

The information shared in these Guidelines contains a lot of reflection and editorial comments because it has been gathered from the real-life experiences of consumers, parents, providers, and other caregivers. The advice and cautions given reflect the current state of affairs in regard to services and supports. No doubt it is peculiar to the generation that grew up in the 80's. We know that for parents many aspects of this service system have improved tremendously over our lifetimes and we hope it will continue to improve. **These Guidelines tell it like it is, as it is known, at the time of this writing.**

*One generation plants the tree; 2 another gets the shade . . .*

The straight factual information has been gathered from the best of resource manuals, research articles, other print sources, and Internet websites. This guide does not provide information about specific support providers. These Guidelines are intended to help you think about what you, the consumers and families want, and then help you find the providers, evaluate their programs, and make an informed choice before selecting services. **Our commitment is to put the best information available all in one place so you would not have to spend your precious time looking for a life but could use it getting a life.**

### **Who We Are and Why We Did This:**

There were essentially three of us working on this project since its beginning one year ago, in 2002. One is Beth Richardson, Director of the Leadership Institute, who has 30 years of experience as an administrator and provider of services for individuals with disabilities. Because of her experience in state government, she already was in touch with national issues and trends. Nevertheless, she spent months doing research on the various topics, especially Medicaid and Medicaid/Managed Care information. She is especially interested in health and wellness information and aging issues.

Jan Barthle, the second member of the team, is a retired special education teacher of 28 years experience at the elementary and university level, but more importantly, is the mother of a charming and challenging young adult with multiple physical, communication, and behavioral restrictions. Melissa has taught her parents well over the years about advocacy and the mental retardation/developmental disabilities service system.

Ray Goodman, whose last name describes him well, worked at the Institute and the Council as a consumer advocate and trainer for two years before and during this project. He wrote many of the "Voice of Consumer Experience" pieces for these Guidelines and helped us all stay grounded in reality.

These are the faces of the three people you see on our cover. They are the main contributors to these Guidelines, but there are many others who stand along side of us. They are the 60 plus consumers we delighted in during the two years of self-advocacy training that proceeded this project, and the 15 consumers and 20 plus parents/caregivers who endured our trial run of this information in workshop form.

**Now as to the WHY?** Each of us has very personal reasons for being a part of these Guidelines.

*One generation plants the tree; 3 another gets the shade . . .*

(Beth Richardson) Over the years I have developed an understanding that information really does empower people and is the key to getting what a person needs and wants. However, it never seems that the information is easy to find, or is out there for consumers of services. Obviously, some people are more tenacious than others, and will work and work to find out what they need to know. All those who do not have the personality (or time) are often left behind. This has made me vigilant to find ways to assist others to access and navigate systems.

(Jan Barthle) As the parents of a child, teenager, and then adult with disabilities, my husband and I experienced everything in these Guidelines first hand and we learned it all the hard way, as many of you are doing right now. And we are relieved to be able to tell you that, at this time, our daughter has a full life as a participant in a great continuing education program and has her own apartment in a 24-hour staffed complex. She is also an artist, and at present is looking for employment with an agency that, when she lived at our home, had her placed part-time in a rehabilitation-designed workstation in a public library.

But it was not always this way! A stunning moment arrived for us about four years ago when we attended a day long workshop presented by Kathleen Bolduc, who wrote a book about her son with autism called, **His Name Is Joel.** At that point, my husband and I were completely exhausted, (and had been for about eight years) and the last thing we wanted to do was hear about some other parent's problems. However, we did drag ourselves there and one of the exercises she had us do after her presentation was to think of a metaphor or analogy that would best express the worst time in our lives with our loved one with disabilities. When it came to my husband's turn, he said, **"I feel like I'm in a storm-tossed sea without a life raft!"** Have you ever felt like that? Well then you know why we wanted to work on these Guidelines.

The official name of this project is: ACCESS-ABILITY: Learning to access and navigate the mental retardation, developmental disability service systems. **We sincerely hope the information in these Guidelines (plus the backup names and numbers of parents in our Outreach Program), and the caring staff and wonderful information on resources at the Council on Mental Retardation and Leadership Institute will be a "life raft" to you!**

(Ray Goodman) When I worked at the Council I wanted to help people understand that people with disabilities are people too. I helped people with disabilities to speak up for themselves. I told people my experiences growing up and that I had a good childhood and made lots of friends. I talked about the hats I collected over the years that have a sports or vacation connection. I like to talk about my life and my experiences and what I have been through. For

*One generation plants the tree; 4 another gets the shade . . .*

example, I started to ride regular TARC when I was around 12 years old and to this date, I still ride a regular TARC bus. I think there should be more money in the budget for housing and transportation. To me housing is a big issue because I feel like there should be homes for people with disabilities when their parents are no longer around.

We, the people with disabilities have the right to vote and work in the community. I think we should stand together in unity in this community. I want other consumers to know there are lots of good people who care about and understand people with disabilities. I hope these Guidelines help do that.

### **Why This Is Important**

The writing of these Guidelines has a very familiar motto at its source, "Information is Power"! **What we don't know can and will hurt us and will hurt the futures of our children and young adults.**

If we are to come to the full empowerment of parents and consumers and the participation of each person with a disability into a full and meaningful life experience, we have to know what we can access (bring into our control) and know how to navigate (find a clear path to our destination) through the maze of system logistics and logjams.

As so often throughout these Guidelines, we are going to use the comments under this heading from the website called the "Quality Mall." This website, for which we will give a full citation later, addresses almost every issue revolving around the lives of persons with disabilities. The information under each issue heading is managed by an expert in that particular area of research, so you get the information and opinions backed by years of study and experience straight from the source.

The last five years of advocacy efforts in Kentucky has taught us that in regard to consumer-directed supports, **"we need to work together to create systems in which all people with disabilities receive the support they need to create their own lives, supported by those who know and care about them, connected with and contributing to others in our communities."**

**<http://www.qualitymall.org>**

Thus we count on you to use and spread the word to other parents and consumers regarding this resource and what you have learned through your experience. We also count on you to give feedback to us about how these guidelines work or do not work! **Our number, for the Leadership Institute is 587-6500. Call us with your information or update today.**

*One generation plants the tree; 5 another gets the shade . . .*

## How This Guide is Organized

There are a number of sections or chapters in the Guidelines. Each chapter begins with:

- **An introduction** to the topic addressed, **and a discussion of why this is important,**
- followed by **a checklist of issues, considerations, options, or alternatives** for the topic presented.
- Each section offers **factual information, program descriptions, eligibility criteria, and contact information,**
- **a presentation of best practices or visionary philosophy,**
- and then a discussion of **Vision vs. Reality** which tells what the present state of supports and services appears to be,
- **Opinions and advice** are also included. Almost every section has a “Voice of Experience” offering from a consumer, parent or provider.
- In some sections, a set of very important considerations were included from a great resource called **“Through Asking the Right Questions...You Can Reach Your Destination”** Don’t miss the reference in later sections so you can get the entire set of questions.
- There is an **Advocacy Needs** listing at the end of each section so that if you want to work toward a better way to do things, you will know where to start.

## Where We Got Our Information and Who Helped Us

Much of the specific information on names, addresses, and phone number of providers, organizations, and agencies came through the courtesy and cooperation of Seven Counties Services, particularly Becky Wolf-Klein, and their wonderful resource guide called **Building Your Future**. It is referenced numerous times throughout the Guidelines.

The Cabinet for Health Services, Kentucky Department for Mental Health and Mental Retardation Services – Division of Mental Retardation booklet entitled **Services and Supports for People with Mental Retardation and Developmental Disabilities** was also valuable especially in regard to information about Medicaid waivers. In addition, The Department of Medicaid Services staff was essential in securing the information on the subject of Kentucky’s Managed Care Program.

Another great **Resource Manual for Persons with Disabilities, their Families and Services Providers** guide is a handbook of program descriptions, eligibility criteria, and contact information developed by the Human Development Institute of the University of Kentucky. Information from this manual was very

helpful in making sure all the relevant categories were covered and has been a tremendous resource to consumers across the Commonwealth of Kentucky.

Many of you who are interested in the plans for the expansion of funding and services under the Supports for Community Living Waiver should see **Kentucky's Plan: From Dreams to Realities for Quality and Choice for All Individuals with Mental Retardation and Other Developmental Disabilities**. This booklet describes the plan developed by the Commission on Services and Supports under House Bill 144 and reports the major recommendations of each subcommittee established by the Commission. It discusses the areas of prevention, promoting choice, promoting quality, promoting access, financing the system, and next steps.

Especially helpful were the resource materials gathered by the **Council on Mental Retardation** staff for particular projects, for example, the "Family Support Groups" list from **FIND of Louisville**. Another excellent resource for us and for you is the **Find-a-Future website**. This and other information from and about the Council's many other excellent programs can all be found in these pages.

### **SPECIAL THANKS**

The Guide was made possible by the Center for Health Care Strategies that directs national programs on behalf of two major health care philanthropies: The Robert Wood Johnson Foundation and The Annie E. Casey Foundation. In addition, CHCS has been awarded grants from the David and Lucile Packard Foundation and the Commonwealth Fund. Their funding, technical assistance and over site was the impetus in bringing this concept to fruition.