

Financial Concerns

Financial Concerns / Estate Planning Assistance

WHY THIS IS IMPORTANT

We are working together **to navigate and 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.** One of the biggest worries in a parent's life is how to make a good life for their loved one in the present and how to ensure that their son or daughter will be safe and financially secure in the future. Families and individuals with disabilities can benefit greatly from an increased awareness of the various approaches to financial planning. Life is tough enough for the person with a disability without the even greater burden of living in poverty. If one is poor, one is completely dependent on other people. The self-determination we have written about so often in this guide means having control over your environment (where and with whom you live), and having options and choices (real ones, not just those that fit into the service system).



Choices also mean control over money. For individuals who receive private or public funding, the capacity to direct that funding towards purchasing supports and services that they need and to be able to obtain them is one very necessary component of self-determination. So financial and estate planning is the process of ensuring that the assets of families and, when necessary, public funding, are available to your sons and daughters during the parents' lifetimes and after they are gone. In this section, we will discuss several revenue sources that are available to most individuals and give you information about the government-funded programs you might obtain.

CHECKLIST OF OPTIONS, ISSUES, ALTERNATIVES

- ✓ Early Periodic Screening, Diagnosis, and Treatment Special Services (for persons under 21)
- ✓ Financial support from parents
- ✓ Wages from employment
- ✓ Center for Accessible Living Benefits Counseling
- ✓ Public benefits
- ✓ What to expect when you apply for public benefits
- ✓ What to bring with you when applying for public benefits
- ✓ Supplemental Security Income (SSI)
- ✓ Social Security Disability Insurance (SSDI)
- ✓ State General Funds
- ✓ Kentucky Supported Living Grants
- ✓ Medicaid (medical card)
- ✓ Managed Care Plans (PASSPORTS and KenPac: See Health and Medical Care Section)
- ✓ Home and Community Based Waiver
- ✓ Supports for Community Living Waiver
- ✓ Acquired Brain Injury Waiver
- ✓ Estate Planning: Special Needs Trust Fund
- ✓ Advocacy Needs

APPLYING FOR SUPPORT: MAKING IT OK TO ASK FOR HELP

For many families, needing to ask for help is one of the most difficult parts of having a child with a disability. American culture strongly emphasizes making it on your own, not asking for a handout, and being independent. Getting public assistance carries a lot of negative associations for some people. Many people who need help desperately are never reached because they are afraid of government programs. Recently, it was reported that an elderly father who was offered a Supports for Community Living Waiver to help with the care of his aging son, refused the waiver until it was explained that his son could remain with him in the home. The father thought the “state” would take his son away if he accepted funding. Proper financial support can actually prevent the need for out-of-home placements. It is essential that family support not be perceived as a handout, but rather a helping hand that enables families to meet the needs of their children with disabilities and allows them to remain in the home as long as the individual with disabilities and his family desires.

Family support programs have to work hard to make sure that their services are seen as positive by hard-working, care-giving families and the general public. When families apply for services, they need to be treated with respect and dignity. Families need to feel comfortable and safe enough to ask questions.

The application and application process should be simple and straightforward. For families whose primary language is not English, staff who speak the family's language or an interpreter should be available. Guidelines for eligibility should be stated clearly and families should be made aware of appeal or grievance procedures if problems arise or services are denied.

Families, service providers, and policy makers must make a conscious commitment to the belief that family support means "doing whatever it takes."

WHAT ARE SOME FINANCIAL CONCERNS MANY FAMILIES HAVE?

Obviously, you know by the time your children reach young adulthood what kind of special needs they will have and can project what kind of living arrangements will be needed and possibly the cost of these if they are outside the family home. Then, of course, there is the matter of medical care, the cost of prescriptions, if needed, and all the other expenses that make up daily life. Most parents may not have the financial resources to cover all these anticipated expenses. There are some important ways you can receive financial help. SSI and SSDI may provide you with the financial base your son or daughter needs to enter the adult community. Both programs are administered by Social Security and have special incentives to allow persons with disabilities to be employed in their communities. A Medicaid card will give you access to needed services as well as provide funding for medical services. On the next few pages, we have tried to provide basic information about these resources and how to apply for them. **It is important to apply even if you think that you are not eligible for services. It is better to be turned down than to take the chance of missing out on important benefits. Also, you may appeal any denial of benefits.**

Don't get discouraged if the process seems complicated; the rewards are worth the time and energy you have to put into the application process.

The information provided here should be used as a guide. This material is very complex and difficult to understand so be sure to call the offices listed under each section to answer any questions you may have.

THE CENTER FOR ACCESSIBLE LIVING: The Center is a valuable local resource for help and information. Their mission is to “assist in providing an environment that supports the individual with disabilities in attaining independent living and the right to choose his or her personal degree of independence.”

The services offered by the Center include **Benefits Plus counseling** among many others. In their Benefits Plus service, benefit specialists are available to assist SSI and SSDI disability beneficiaries, family members and professionals with:

- Information on medical benefits
- Social security
- Transitional assistance
- Public housing
- Personalized benefits planning
- Help to understand how working affects benefits
- Ongoing assistance on issues concerning benefits

Their office is located at 981 South Third Street, Ste 102, Louisville, KY. 40203 or call (502) 589-6620 (voice) or (502) 589-6690 (TTY) or reach them through e-mail: info@calky.org or their website: www.calky.org.

SPECIALTY FUNDS

EARLY PERIODIC SCREENING, DIAGNOSIS, AND TREATMENT SPECIAL SERVICES (EPSDT)

Effective March 1, 2002, a Federal Court ruled that for children and youth with severe mental impairments, medically necessary services including case management, evaluations, and special therapies, must be provided through EPSDT. These services previously were not covered through this program in Kentucky, and may offer great benefit to children who need community and home services beyond what they receive through their school program. Severe mental impairments include disabilities such as autism and mental retardation.

To be eligible for this service, you must be younger than 22 years of age and be eligible for Medicaid. **This information is especially important for youngsters between 18 and 22 because your son or daughter can apply for Supplemental Security Income (SSI) based on his/her own financial assets (or the lack of them) at age 18. And as will be explained further in the body of this section**, when your young adult qualifies for SSI, he or she will automatically be eligible for Medicaid. **EPSDT allows Medicaid service providers to supply necessary medical, vision, hearing and dental services that are not otherwise covered by Medicaid, to eligible children and adolescents up to age 22.**

Required information for patient application for services includes:

- A physician's order
- Product information
- Prices from different providers with comparable products

Applications must be submitted by the service providers, often through a home health agency, nurses' registry, dental agency, or equipment provider. (Call Seven Counties at 459-5292 for a list of local EPSDT providers.) For further information contact the Children's Health Services branch of the Ky. Department for Medicaid Services, 275 E. Main Street, Frankfort, KY. 40621 or phone 1-800-635-2570, (TTY 1-800-838-5085)

If you are refused services through EPSDT, there is an appeal process. For questions about appealing a decision, contact the Kentucky Division of Protection and Advocacy at <http://www.kypa.net> or phone 1-800-372-2988.

SPECIAL NOTE: Even with the current Medicaid cutbacks, families of children under 21 on a waiver can receive EPSDT services and supports for their children above the waiver dollar limit if the services and supports are medically necessary. Personal Care services could be considered medically necessary and could not be limited by the waiver dollar limitation. **Since EPSDT is a Federal Program for all children, personal care services are part of the Medicaid state plan. They are not optional waiver services.** Therefore, there should be no limitations if a child under 21 requires personal care services as a medical necessity.

PUBLIC-BENEFIT PROGRAMS

If you have never entered the public benefits system before, the process will come as quite a surprise to you. **Be sure to read all the survival information below before you call or apply. A major word of advice - if you ask a question of a government program worker over the phone, or even sometimes in person, do not take what they say as the gospel truth. Get a second opinion!** The regulations and interpretations sometimes are so complex that not even the people working in the program always keep them straight. Here is where the Benefits Counselor from The Center for Accessible Living can provide checks and balances on your problem. Also before you apply for SSI, be sure to ask an expert in benefits how to answer certain questions about how you are considering or covering your dependent's cost to the family in order to support/maintain them in your home, because **the way you answer the question may determine your loved one's eligibility for assistance.**

SUPPLEMENTAL SECURITY INCOME (SSI)

SSI is a nationally funded program of the Social Security Administration that is administered by each state. Regardless of whether you have worked or how long you have worked, anyone can apply for SSI because it is based on financial need. It pays monthly checks to people who are elderly, blind, or have disabilities and who don't own many things or have much income. You must be determined disabled by the Social Security Administration. For SSI eligibility, a disability is defined as a physical or mental problem that is expected to last at least a year, or result in death, and keeps a person from full employment. You can apply by calling the Social Security office for information or an appointment at **1-800-772-1213** or go to their website at <http://www.ssa.gov>. You may also call for an appointment and apply at the local offices listed below. Office hours: Monday 8:00-4:30, Tuesday-Friday 9:00-3:30. **Be ready to wait, the numbers are almost always busy.**

Louisville West Office at 3133 W. Broadway **775-5709**
Louisville East Office at 10434 Shelbyville. **244-0593**
Louisville Central Office at 600 W. Broadway **582-6690**

Persons can go to any convenient site regardless of their zip code.

INFORMATION NEEDED TO APPLY:

Depending on your circumstances, you will need some or all of the documents listed below:

- Birth certificate
- Social Security Card

(See information below if you don't have these documents or can't find them.)

- W-2 forms or self-employment tax returns for last year
- Depending on your circumstances, you may need proof of income for everyone in the family, pay stubs; or proof of assets for everyone in the family, bank statements, deed to the house, title to car, burial plots
- Household expenses such as rent receipts, utility bills, medical bills, child care expenses
- Name of your bank and your account number so your benefits can be directly deposited into your account.

Don't delay making the application. Even if you are missing some papers that you will need, do not wait to start the application. Start the process, because benefits are backdated to the date of application. You can always return with the necessary papers. You will need to submit original documents or copies certified by the issuing office. You can mail or bring them to Social Security. They will make photocopies and return your documents. Be aware that once you fill out the application, it could take up to nine months before you hear back from the office.

(The information above is also available in greater detail on the Kentucky Cares Tip Sheet at their website: <http://www.kycares.net/needsassessment/tipsheet.asp?tipid+1656>)

PRACTICAL CONSIDERATIONS:

WHAT TO EXPECT when applying for public benefits.

You should be prepared to visit public benefits offices at least twice. You should call ahead for an appointment to make an application and plan on spending all day. The best times to call or make an appointment are in the middle or toward the end of the month. Avoid the beginning of the month if possible because this is when lots of people may call about their checks. Be sure to ask them what you need to bring to make the process go more smoothly. There is no way to anticipate all the possibilities. The Social Security office is always busy. Each visit may include a long wait, possibly all day. Do not let this stop you. You may need to make arrangements for after-school care if you have youngsters at home. Do not assume that you will be home in time for a younger child's return from school. You do not want to leave after waiting all day without accomplishing some steps in the application process. If you must bring children or someone you take care of along with you, bring a snack and something for him/her to do. It is also a good idea to bring a snack for yourself and something to do while waiting.

REMEMBER ALL THE TIME YOU ARE WAITING THAT IT IS WORTH THE WAIT. SSI RECIPIENTS IN KENTUCKY AUTOMATICALLY ARE ELIGIBLE FOR MEDICAID.

WHAT TYPE OF DOCUMENTS SHOULD I HAVE AND WHERE CAN I GET THEM IF I DON'T ALREADY HAVE THEM:

Birth Certificate: If you do not have your original birth certificate, you will need to obtain a copy from the state in which you were born. If you were born in Kentucky, you may attain a certified copy from:

The Office of Vital Statistics Call (502) 564-4212
275 E. Main St. 1E-A
Frankfort, KY 40621

If you were born outside of Kentucky, look in your local library for the telephone directory of the city and state of your birth. Look for the address and phone

One generation plants the tree; 7 another gets the shade . . .

number of the Bureau of Vital Statistics, or dial 1+area code of the birth county + 555-1212 and ask for the Bureau of Vital Statistics.

If you would like a certified copy sent to your address, allow 30 days for delivery. The cost at present is \$10.00 and you may send check or money order. Send the following information with your request:

- Full name at birth
- Month, day, and year of birth
- County of birth
- Mother's maiden name
- Father's name

Be sure to send the following information as well:

- Address of where to mail the certificate
- Phone number where you can be reached between 8:00-4:30 during the day
- Number of copies needed

Social Security Card

For information on obtaining a Social Security Card, phone the Social Security Administration General Information number, 1-800-772-1213, or go in person to the Social Security's main office at 601 W. Broadway, telephone number 582-6690. United States citizens need a copy of their birth certificate or baptismal record. Non-U.S. citizens need their birth certificate and a legal paper, such as a passport or visa.

Identification Card

It is very important for you to carry an identification card with you at all times. If you do not have a driver's license, you should have an ID card made. You can apply for an identification card at any driver's license office for a fee. Call for the branch nearest you and ask what to bring with you. You must be 12 years or older and there are several documents you may need to present in order to have an ID made:

- Two items of identification, one of which must list full name and date of birth, and a second supporting document, such as
- Birth certificate, School record with date of birth, Baptismal certificate, Family Bible record, Passport
- Social security card
- Parent or guardian present

SOCIAL SECURITY DISABILITY INSURANCE (SSDI)

Social Security Disability Insurance is a federal payment program for workers with disabilities. A person is considered disabled when he or she has a severe physical or mental impairment or combination of impairments that prevents him or her from working for a year or more.

TO RECEIVE BENEFITS UNDER THE SSDI PROGRAM, YOU MUST HAVE WORKED LONG ENOUGH AND RECENTLY ENOUGH UNDER SOCIAL SECURITY TO BE INSURED. OR IF YOUR PARENTS ARE OF RETIREMENT AGE AND YOU ARE OVER 18 YEARS OF AGE, YOU MAY ALSO BE ELIGIBLE FOR BENEFITS. THE CREDITS YOU OR YOUR PARENT MUST EARN TO BE ELIGIBLE FOR SSDI ARE BASED ON THE AMOUNT OF MONEY EARNED, TIME SPENT IN THE WORK FORCE, AND AGE AT THE TIME OF DISABILITY. IF YOU THINK YOU MIGHT QUALIFY, CALL THE SOCIAL SECURITY OFFICE LIST ABOVE FOR FURTHER INFORMATION.

“WRINKLES”: Eligibility for both SSI and SSDI is possible if SSDI benefit rates are low enough. **Further wrinkle:** This then makes the recipient eligible for both Medicaid and Medicare. This will be discussed in the next section. **BIGGEST WRINKLE:** **If your adult son or daughter now receives SSI, when one of the parents retire and draws on his/her SSI, the adult “child” will then be switched to SSDI status and may lose her/his medical card for up to two years unless he/she is in a Medicaid Waiver Program such as Supports for Community Living or Home and Community Based Waiver Services or other qualifications which will be discussed in the Medicaid section under “List and Definition of Medicare/Medicaid Dual Eligibles”.** Your disabled son or daughter is considered your dependent no matter what his or her age. That is why he/she will be automatically transferred upon your retirement.

KENTUCKY SUPPORTED LIVING

This program offers assistance to individuals covered by the Americans with Disabilities Act (ADA). **It is a flexible program that provides individualized services that are managed by consumers and their families.** Some of the services provided by Supported Living include but are not limited to:

- respite
- training
- personal care
- transportation
- community resource development
- home modifications

There are two **categories to the grant application – one-time expenses or start up costs, and ongoing expenses.** So for some projects, such as home modification or adaptive equipment this may be the only obtainable funding and **it is only granted if** there is no other funding source available for the same adaptation or service.

A waiting list for this service is not maintained but funding is limited and is competitive. **Individuals with disabilities in Kentucky have direct control over funds only in the Supported Living Grant program.** It must be mentioned immediately that this program is funded by State General Funds rather than Medicaid federal-matched dollars and therefore it has very limited funds considering the demands for its supports.

Grant requests are due at the end of March each year. Application assistance is readily available from Seven Counties or from the Supported Living Regional Coordinator: Call Becca Krall at 459-8221, your support coordinator at Seven Counties, or just call 459-5292 and ask for help on this application.

VOICE OF EXPERIENCE FROM A PARENT

"The Supported Living Grants have been a "lifesaver" for our daughter – she has received grants for an automatic door opener for her apartment, a hydraulic bath chair, and other one-time grants that have helped her live more independently. She also receives an ongoing grant for art therapy from a wonderful therapist, Julie Cole. The development of her artistic talent has given her life a dimension that would not otherwise be possible – she is perceived much differently as an artist than as her more visible presence as a young woman in a wheelchair who is nonverbal and from whom not much is expected.

Her artistic endeavors have also led to community involvement in Art Fairs at which she sells her paintings and another income earning cyber-connection financed by a one-time grant, her own website www.Melissasart.com on which she displays her work. Supported Living leads to "quality of life" enhancements that would never be considered necessary under a Medicaid waiver which, as helpful as it is, is essentially a medical model. It is also the only public-funded financial source that follows the philosophy of self-determination."



MEDICAID

Why is Medicaid Important to you and your Family?

Medicaid is typically the only primary health insurance plan for persons with disabilities who have limited income. The lack of adequate health insurance is often cited as a primary barrier to both the ability to live in the community and the ability to succeed in employment. Therefore, an increasing number of individuals with disabilities are looking to Medicaid as their primary health insurance plan, notwithstanding higher level of income. Medicaid may be available to those individuals through state specific Medicaid waivers.

One generation plants the tree; 10 another gets the shade . . .

Medicaid – What is it anyway?

Medicaid is a federal-state matching entitlement program that provides medical assistance for certain individuals and families with low incomes and limited resources. Medicaid is the largest program providing medical care to eligible needy persons. You may qualify for Medicaid services based upon your disability and/or income.

You may have heard the word **Medicare**, which is a federal health insurance program and is associated with Social Security benefits. Medicare is, for the majority of persons with disabilities, an inferior health insurance program compared to Medicaid. Note: For the purpose of this guide, we will only focus on Medicaid.

Basis of eligibility and maintenance assistance status

Medicaid does not provide medical assistance for all poor persons. States generally have broad discretion in determining which groups their Medicaid programs will cover and the financial criteria for Medicaid eligibility. You may qualify for Medicaid in one of three different ways:

- 1) If you receive SSI, you will be automatically eligible for Medicaid.
- 2) If your income exceeds the qualification for SSI because you receive SSDI, you are eligible for Medicaid. You will probably have to pay a predetermined amount toward your medical bills based on your income. This is called a spend down.
- 3) **If you are denied SSI due to excess earnings, but not due to your medical disability, and your income does not cover your medical expenses, you may still be eligible for Medicaid.** People whose primary disability is mental retardation are frequently eligible for Medicaid under this qualification. If you are denied SSI based on having too many **resources**, you are not eligible for Medicaid.

As stated above you must meet the “income and resource” test. Income is defined as anything received in cash or in kind that can be used to meet needs for food, clothing or shelter. **Resources** are defined as cash or other liquid assets or real or personal property that an individual owns, and could convert to cash, which can be used to provide for food, clothing or shelter.

People with disabilities should use to the maximum any exclusion from income and resources (i.e., things that meet the income or resources definition but are specifically excluded) and structure (or restructure) the receipt of any money flowing to the SSI applicant or recipient so that it will not meet SSI'S definition of income or resources.

Be prepared to provide Department of Community Based Services with the information they will need to determine eligibility.

How Can I Apply?

You may apply at the **Department of Community Based Services (DCBS)** office in the county where you live. To make an appointment in Jefferson County, call **502-595-4238** or visit their office at **908 W. Broadway**. For other counties look in your telephone directory in the blue pages under State Government for the Cabinet for Families and Children-Department for Community Services.

You can pick up an application for Medicaid at the DCBS office. At that time, you should arrange an interview to discuss your application. If you have any questions, please call your DCBS office and ask to be referred to the worker of the day. This office is busy. You are more likely to reach the worker if you call after 11:00 a.m.

Keep in mind that many of the services under Medicaid are federally mandated services. ***All other services provided for under the Medicaid State Plans are optional services under the Federal requirements and may be eliminated during periods of the State's fiscal shortfall.***

If you cannot get answers or help at the local level, **call State Division of Systems and Member Services, Mary Rhodes, present Director, at 1-(502) 564-5183** or call the Kentucky Cabinet for Health Services Ombudsman: Toll-free 1 (877) 807-4027. **The CHS Ombudsman serves as a health services information and communication resource, an advisor and dispute resolution office for Medicaid, Public Health, and Mental Health/Mental Retardation Services.**

LIST AND DEFINITION OF MEDICARE/MEDICAID DUAL ELIGIBLES

Medicare has two basic coverages: Part A, which pays for hospitalization costs; and Part B, which pays for physician services, lab and x-ray services, durable medical equipment, and outpatient and other services. Dual Eligibles are individuals who are entitled to Medicare Part A and/or Part B and are also eligible for some form of Medicaid benefit depending on the category under which they fall.

There are 8 different categories of Dual Eligibles, the descriptions of which use such terms as Qualified Medicare Beneficiaries (QMB Only and QMB Plus) and Specified Low-Income Medicaid or Medicare Beneficiaries (SLMB Only or SLMB Plus) or Qualified Disabled and Working Individuals (QDWIs), etc. This is more than you ever wanted to know but if you have to know: see the following website <http://cms.hhs.gov/dualeligibles/whois.asp>. We have hard copies of the information

here at the Leadership Center but cannot give you any guidance on it so your best bet is take your individual case and questions to a Benefits Counselor.

KENTUCKY MEDICAID WAIVERS (OPTIONAL SERVICES)

Before we go on to discuss waivers, you might want to know what a waiver is. A waiver is granted when the State requests that certain regulations do not apply, so that they may use Medicaid funds to pay for services outside of a long-term care facility. Remember that Medicaid is basically a medical insurance program for people who need medical care, sometimes in a nursing home. Persons with mental retardation or developmental disabilities are not really "sick" and often have a permanent disability like cerebral palsy that will not be cured. But, they do not need to be in a nursing home, especially when they are young adults. Yet, in order to give Medicaid benefits to people with disabilities, waivers such as the Home and Community Based Services waiver are granted to persons who would "otherwise" need nursing home care, for example, the Home and Community Based Waiver. But the bottom line is that these waivers are still based on a medical model.

Community Waivers that are typically used by people with developmental disabilities in Kentucky are the:

- Home and Community Based Waiver
- Supports for Community Living

HOME AND COMMUNITY BASED SERVICES WAIVER

The Home and Community Based (HCB) Waiver program provides necessary medical services to Medicaid eligible persons who are aged or disabled that would otherwise require a nursing facility level of care. Services include but are not limited to the following:

- ✓ Assessment and reassessment
- ✓ Case management
- ✓ Homemaker services
- ✓ Personal care services
- ✓ Respite
- ✓ Minor home adaptations
- ✓ Attendant care
- ✓ Adult day health care

A Home Health Care Agency selected by you, conducts an assessment. (A list of Home Health Agencies is found below.) From that assessment an individual written plan of care is developed that includes: 1) all your service needs; 2) amount and duration of services(s) to be provided, and; 3) choice of service provider(s). Be sure that all of your service needs are written in the plan before you sign it. **The federal government will not reimburse for waiver services that are not included in this plan of care.** *Your plan will then be reviewed and authorized by a Medical Review Board in Frankfort before such a plan can be carried out.*

At the time of this writing there is no waiting list for this program; however, recently, there were serious restrictions placed on the program and many present recipients are not being recertified. Your right to appeal if these services are denied is explained below.

THE HARSH REALITY - Funding for Home and Community Based Programs:

Until recently, many adults with disabilities who could show medical need were quite routinely financially supported through the Home and Community-Based Services Waiver. As explained above, this waiver was established to provide funding for necessary medical services to Medicaid eligible persons who are disabled and/or elderly who would otherwise require nursing facility level of care. One can only obtain this waiver through a Home-Health Agency, which does an intake procedure and then processes a person's application through a Medical Review Board set up in Frankfort.

In the past, many people with disabilities who needed some medical procedures or whose condition required medical monitoring were given this waiver to receive personal care and other services in their homes and/or attend day habilitation programs. However, the criteria for eligibility was revised in the Administrative Regulation 907 KAR 1:022 in April of 2003 to "ensure that only the most acutely ill or medically needy individuals qualify for Nursing Facility services.....to eliminate **the inconsistency and confusion of overlapping Personal Care level of care criteria.**" **Under tightened rules, persons who want to obtain these services must now need at least three services every day from among the following: assistance with mobility, help with confusions or agitation, feeding, using the toilet, medication, injections, physical therapy, cognition and communication, dressing, bathing and grooming.** (There are complex details in the regulations about all of the above so you need to check those before you can really understand how medically oriented these criteria are.)

At present the state is using a contract agency, Health Care Review Corp., to review client files to determine whether it appears some people can care for themselves. If its doctors and nurses decide they can, the clients get a notice they are being cut off Medicaid for nursing homes or home and community services. The reviewers rely on records from the facility or company that provides the service – such as a home health agency – and don't necessarily see the individual. A physician's opinion is considered, but not required. At present, many persons currently approved for the HCB Services are being denied this waiver when their current recertification date rolls around. **If you receive a letter of denial for the Home and Community Based Waiver for the person in your care and you want to appeal the decision, take the letter of denial immediately to the Home Health Agency that serves you and they will help you formulate an appeal.**

Clients have the right to appeal and they cannot be cut from the program while the appeal is pending but they must appeal within 10 days to maintain services.

Since the state started using the new rules, over 1,000 people seeking assistance in the community, like home services for the disabled and therapy for emotionally disturbed or autistic children, have been denied Medicaid services. Meanwhile, the number of appeals is growing to more than 1,000, and Medicaid is seeking additional hearing officers and lawyers to help handle the caseload. It is predicted that hearing dates are being set for up to ten months in the future at this time.

Meanwhile, testimony from hearings that are required when the state issues a new regulation will be sent to state lawmakers who must review the rule change made by the Cabinet for Health Services. If legislators reject the changes, they will expire by the end of the 2004 legislative session. Perhaps by that time we will have better news.

Home health care providers who have been approved by Kentucky's Department of Medicaid Services (DMS) provide services. A current list of providers is available below or through the Department of Medicaid Services @ (502) 564-5183 or Seven Counties, @ 502-459-5292 or your local Comprehensive Care Center

Home and Health Agencies

Caritas Home Health 1-800-779-0705 1-502-366-6055	Interim Home Health 1-502-897-2255
Caretenders Home Health 1-800-928-2863 1-502-238-5150	Intrepid USA (formerly Med Shares) 1-800-267-0592 1-502-425-1227
Gentiva Health Services 1-502-895-4213	North Central Home Healthcare 1-502-222-0174
Family Home Health 1-502-633-3007	Visiting Nurses Association 1-502-581-8621

How to Apply

The Home and Community Based waiver may be applied for by contacting one of the agencies listed above or your local Department of Community Based Services office at **502-595-4304**.

SUPPORTS FOR COMMUNITY LIVING WAIVER

The Supports for Community Living (SCL) waiver is a home and community based waiver under the Kentucky Medicaid program and was developed for Kentucky residents as an alternative to institutional care for an individual with mental retardation or developmental disabilities.

Services include:

- ✓ Support coordination
- ✓ Residential supports
- ✓ Community habilitation
- ✓ Supported employment
- ✓ Community living support
- ✓ Behavioral supports
- ✓ Psychological services
- ✓ Occupational therapy
- ✓ Physical therapy
- ✓ Speech therapy
- ✓ Respite

(A complete description of each service area may be found in the guide, [Services and Supports for People with Mental Retardation and Developmental Disabilities](#), published by the Cabinet for Health Services, and available from the Division of Mental Retardation, 100 Fair Oaks Lane, 4th Floor, Frankfort, Ky. 40621.)

The SCL waiver does have a waiting list

Resources are very limited, and this makes it extremely important for families to plan for the future of their dependent adults. There are some estimated 8,000 people with disabilities in Kentucky currently eligible for the Medicaid waiver called Supports for Community Living. There is currently a 2,000 person waiting list. See Advocacy Needs below.

Eligibility

To be eligible for the SCL waiver you must have mental retardation or a developmental disability and meet the requirements for residence in an Intermediate Care Facility for persons with Mental Retardation (ICF/MR) and meet other Medicaid requirements.

SCL providers must be certified by the Division of Mental Retardation. Current Region VI Supports for Community Living Providers List can be obtained from Seven Counties Services at 459-5292 or by contacting The Division of Mental Retardation at 502-564-7702 to receive a complete list of certified providers. You may also go to the provider link at <http://mhmr.chs.ky.gov>.

How to Apply

To apply for the SCL waiver you must complete a form called MAP – 620 “Application for SCL Waiver and ICF/MR Services” which is included in this guide (along with a Waiting List Validation Assessment) for your information. Be sure to get help from Seven Counties or your Service Coordinator in filling out the application because this application will be used to determine acceptance for the waiting list and service needs.

For an application, you can also call the SCL Area Administration at 502-361-2301 Ext. 2261 or the Kentucky Department for Mental Health and Mental Retardation Services, Division of Mental Retardation at 502-564-7702 for the complete application.

AN HONEST LOOK AT YOUR NEEDS AND THE NEEDS OF YOUR LOVED ONE WHEN FILLING OUT THE APPLICATION:

Take great care to be completely honest about your son's or daughter's needs for support and about your capacity as the caregiver. We know you are not used to talking about private matters, about personal care needs, and don't want to appear incompetent; but in this case, glossing over the hard work and the hard reality will work against you. Primary caregivers over the age of 60, or at any age, may face health and medical issues that may come up suddenly and make it very difficult to continue the level of care your son or daughter deserves.

There is another issue here, too. Although you love your dependent adult with all your heart, how long should an adult really remain at home living with elderly parents? (See Living Arrangements Section) So these questions are not about you, they are about the life you are seeking for your loved one. If you are from the “old school”, we know you would never consider yourself as “needing any help” or applying for something that looks to you like government poking into your business. However, if your loved one is eligible for it, the Supports for Community Living Waiver is a funding source that your loved one will need and deserves to have if he or she is going to live a life of quality instead of poverty.

HOW SCL WAITING LIST VALIDATION IS DONE:

As mentioned in many sections, there is a waiting list at the present time of over 2,000 people with serious needs waiting to receive the SCL Waiver. **How is the need of your son or daughter to be served determined?** Earlier we referred to the Map 620, “Application for SCL Waiver and ICF/MR Services” form. There is another form called the “SCL Waiting List Validation”. The Support Coordinator for your son or daughter or another person appointed by the Division of Mental

Retardation will interview you to determine the status of your loved one as “Emergency, Urgent, or Future Planning” depending on the information you give and the data they have about him/her.

Before you actually go into the office of the person assigned, look at the descriptions under each category carefully. During the interview, give the person validating the status of the individual you represent a complete and realistic picture of conditions and needs. The needs of your son or daughter, along with your capacity as a caregiver, will be carefully documented. The personal welfare, residential status or residential needs, and your ability to meet personal care demands appropriately will be discussed. Your age and the age of your loved one will also be taken into consideration.

After all is said and done, a category of need will be assigned: if it is determined to be an emergency situation, it will mean your child needs immediate attention for the services of the SCL Waiver. An Urgent category means that the person has the need to receive an SCL Waiver within the next year; while the Future Planning category means that services are not indicated within the next year. Should circumstances change in the future, he or she will be reassessed. You should be notified of the status of your loved one very soon after this validation is done. If you do not agree with the findings, contact your Support Coordinator immediately or call the Division of Mental Retardation and ask to speak to Kevin Lightle, Director. **YOUR KNOWLEDGE AND ACTION ARE VERY IMPORTANT IN GETTING THE SERVICES YOUR LOVED ONE NEEDS!**

See insert of MAP-620 Application for SCL Waiver and ICF/MR Services Form at back of this section.

FREEDOM OF CHOICE

Waivers must grant persons who receive the waiver, freedom of choice. Under the Federal Medicaid law (Section 1902 (a) (23) of the Social Security Act) you are guaranteed the right to select from among all qualified providers to provide your supports to you. The fact that a state operates a “waiver” program does not mean that it can ignore this law.

Kentucky assures that each individual eligible for the waiver will be given freedom of choice in selecting qualified providers of each service written in the plan. If you want a variety of providers to service you, as indicated by your support plan, that is your right. If you are denied freedom of choice in provider(s) or services be sure to get the denial in writing. You can appeal the denial. See appeals under this section.

Payer of Last Resort

Medicaid funds may not be used to satisfy a financial commitment for services that may be paid for from another public or private source.

ACQUIRED BRAIN INJURY (ABI) WAIVER

This program offers flexible, temporary services to individuals with acquired brain injuries. This is a community re-entry program for rehabilitation and training. Services include:

- case management
- personal care services
- respite care
- environmental modification
- companion services
- behavior programming
- counseling and training
- structured day programs
- specialized medical equipment and supplies
- prevocational services
- supported employment
- community residential services
- occupational therapy

To qualify you must be 21 to 65 years of age, require nursing level of care and have a primary diagnosis of an acquired brain injury. Among numerous qualifications including being eligible for Medicaid, the person must also have damage that affects thinking, physical, or behavioral abilities or sensory skills and have potential for rehabilitation and retraining.

To Apply: Contact the Brain Injury Services Unit – 1-800-374-9146. The Brain Injury Services Unit will send you a letter with a list of approved ABI Medicaid Waiver Program providers. You may then contact the provider of your choice for an initial evaluation.

AN OVERVIEW OF ESTATE PLANNING

There are two categories of assets to consider when planning your estate:

- 1) probate assets, such as those that would be listed in and controlled by your will;
- 2) non-probate assets, such as life insurance or proceeds from an Individual Retirement Account (IRA) among others, which transfer according to the terms of the contract and not by the terms of your will.

Check with a financial planner or an attorney for more information.

In both cases, so as not to jeopardize government benefits, it is important not to name the person with a disability as an outright heir or beneficiary. You can take one of three routes listed below to accomplish this:

- simply omit the person with a disability from the will. In some states you must clearly state that it is your intent that the person in question (when she or he is your daughter or son) not receive an inheritance from you. This statement of omission is sometimes accompanied by the next items.
- Make a specific gift to an individual (other than the person with a disability) with an informal and unenforceable understanding that the proceeds are to be used for the person with a disability. This cannot be a commitment on the part of the named recipient. If it were a commitment, the gift in question would be considered an asset of the person with the disability and jeopardize his or her public assistance. The informal nature of this agreement means that there are not guarantees that the gift will be used for the benefit of the person with a disability.
- Establish a special needs trust and have the child's share of your assets paid into this trust.

THE SPECIAL NEEDS TRUST

This trust, also called a “supplemental care trust”, receives and manages money for the benefit of your child with a disability. To be sure that needed government assistance continues, the trust must be set up correctly. The trust money may not be used for food, shelter, and clothing. It can be used for items not paid for by government assistance such as medical expenses not covered by the waiver program, dental work, home repair, or education. Make sure to only use a lawyer who has extensive experience with these trusts. A minor error can create a lifetime of problems.

The trust can receive inheritances or gifts. By contributing to the trust, friends and family members can help your child without the concern of jeopardizing government benefits. Money inside the trust can be invested and earn money with no limits. The assets and earnings belong to the trust and not the child or adult. Parents can establish and fund the trust, and act as trustees while they are alive, or the trust can be written so that it is established by the parents' will and starts to function after the parents' death. There are numerous advantages to establishing a trust now.

FUNDING A SPECIAL NEEDS TRUST

Many families believe there is very little money or assets to put into a special needs trust. This is seldom true. You may have more assets than you realize, although some may become available only after your death. Your financial planner can provide major help in analyzing your finances and finding the resources to put into the trust. Some of the possibilities include:

- Insurance, one of the few ways of guaranteeing future funds
- Standard government benefits, such as Social Security survivor benefits
- Savings and investments, including money in retirement funds
- Assistance and inheritances from friends and family members
- Property, such as a family home
- Military benefits

KENTUCKY POOLED SPECIAL NEEDS TRUST

There is a less costly, \$10,000 minimum asset alternative to the Special Needs Trust. For more information on the Kentucky Pooled Special Needs Trust option for persons with mental retardation, **contact Doug Draut at the Cedar Lake Foundation - 425-5323.**

FIND A FINANCIAL PLANNER OR LAWYER

If you are already in a program operated by a service provider, they will be familiar with attorneys who routinely and competently handle special needs trusts. For other recommendations, talk to fellow parents, professionals, or call the Council for Mental Retardation, Parent Outreach Program (502) 584-1239, ask Susan Lawrence for a list of lawyers who have this expertise.

ADVOCACY NEEDS:

1. The **Supported Living Program** described above is asking for **increased funding** in the next legislative session (2004) to meet the increasing number of applicants and also because **it is one of the few self-determination funding streams available to consumers at the present time.** Please lend your support!

2. Although great strides were made in 2000 with the passage of House Bill 144, the present funding and future funding promises will not catch up with the number of people needing this support until about the year 2010. While we are very grateful for the attention this need has received, unfortunately Kentucky had sunk to 49th in the nation in funding for community services for persons with disabilities and one legislative action cannot make up for 30 years of fiscal neglect. **The needs of individuals for the Supports for Community Living Waiver still far outweigh the funds available. The current waiting list is over 2000.**
3. Many, many individuals in Kentucky are still living with parents into their adulthood and the old age of the parents. **It is startling to realize that over 30% of primary caregivers of adults with disabilities are over the age of 60.** If you look realistically at the decline in health and the eventual death of the parent, **there is no doubt that a crisis is in the making** if no real planning is done and no increases in government support are made available.
4. **Change of the essential funding structure and mechanism for persons with mental retardation and developmental disabilities is necessary.** Unfortunately, this means that at the present time, many, many adults with disabilities are not even able to leave their parents' home much less live in the community. The adult service agencies decide whether or not to give you services or to help you based on your funding and how your needs fit into their programs.
5. **Persons with severe disabilities and high intensity needs or individuals with behavior problems or mental illness are most often still denied services because of "frozen" rates or rate reimbursement by Medicaid that is under the actual cost of the services provided.** As much as they would like to, no service agency can support for very long individuals on whom they are losing money. And right now the rates for persons with high intensity needs are not being adequately reimbursed. It is easy for us to see that it would take more highly trained and more highly compensated staff at a lower ratio of staff per client if the person had intense physical or emotional needs. **However, in Kentucky at the present time, those decision-makers setting reimbursement rates are not taking into consideration the higher cost of services in urban areas or the reality that because of the more intense needs of the consumer, lower staff to client ratios are necessary. This lack of comprehension is forcing many individuals and families into crisis.**

WHAT CAN YOU DO ABOUT THIS?

See Advocacy Section for specific forms of action.