

# Living Arrangements / Housing

## Introduction: Where Will I Live As An Adult?

Our understanding of where people with developmental disabilities should live has evolved significantly in the last ten to twenty years. At one time, continuing to live with one's parents into adulthood was a common practice; or living in group homes was considered the best place for people. But many forces have challenged that notion. **Person-centered planning, looking at each individual and his or her preferences and designing living arrangements to meet those desires and needs, is considered a model for best practice.** At the present time, some adults with disabilities must live or choose to live with their parents or in the home of extended family members. Many have a room of their own or an apartment in the home of a relative and may be quite happy there. But let's look at this challenge, if someone lived in his/her own place, a place that was really **home**, what would that be like? How would they get support there? **Whether it is a home they own, rent, or lease, the defining principle needs to be, it is still theirs. The idea that persons with disabilities might want to have their own lives, as independent as possible from their parents, and their own "home" is now pretty much taken for granted.**



It has also come to be recognized that the lives of individuals with disabilities should as much as possible include the important milestones and parallel the **rites of passage that mark the transition into adulthood for persons** considered "typical" in our society. Just because this transition may come at a later age and be planned for and supported more intensely, does not keep it from being desired just as strongly for these individuals as it is for any other adult.

## CHECKLIST OF RESIDENTIAL ALTERNATIVES, OPTIONS

- ✓ Independent living, self-support
- ✓ Independent living, family support
- ✓ Live with family, relatives in own quarters/apartment
- ✓ Rented apartment with friend, roommate – family support
- ✓ Independent living in apartment or home– family support
- ✓ Privately owned home – family support
- ✓ HomeChoice Mortgage program
- ✓ Privately owned home – paid staff
- ✓ Supervised apartment – periodic visits by paid staff
- ✓ Supervised apartment – daily visits by paid staff
- ✓ Supported apartment – 12 hour staff
- ✓ Supported apartments with 24 hour staff
- ✓ Group home with 24 hour staff
- ✓ State operated facility (ICF/MR)
- ✓ Live with family – full support
- ✓ Family care home
- ✓ Personal Care Homes
- ✓ Adult foster care
- ✓ Adult nursing home



**THE VOICE OF EXPERIENCE:** Here is what Ray Goodman has to say to other people with disabilities who want to know what the good things are about moving out of your family home. We also asked, what things are hardest, what things do you miss the most about not living with your parents?

*“I would tell them that moving away from your parents will give them more independence and more responsibilities. But it is important to have family support and friends when you do so. The best part is that you can prove that you can live on your own. You can learn how to cook and clean and do laundry, to show that you can manage your own money and go to the bank.*

*The hard thing is that you are by yourself, there might not be any one to talk to; you will miss your family and someone to drive you to work or the movies. But one good thing is that you can call your friends to see if they would like to go to movies or to ballgames. I am really lucky that I found a new home now where I live with old friends and made new friends.”*

And that brings us to comments on independence offered by Ed Roberts, a leader in disability movements. **“Independence should be measured by the quality of one’s life with adequate supports, and not measured by the tasks one performs *without* assistance.”**

## **SO, WHAT ARE MY CHOICES?**

### **FAMILY-FINANCED HOME OR APARTMENT**

Some persons with disabilities are able to make quite satisfactory living arrangements with the help of their families. Some live in an “apartment” in their parent’s or in a relative’s home. The family may need to support the person in financial or transportation areas or sometimes they even are able to provide family-connected employment, but the person lives quite independently in self-help and self-care areas.

In some cases several families, who know each other or have become acquainted through parent support groups, have pooled their resources to buy a home in which their sons or daughters live with some family support, or paid support available on an interim or continual basis. Sometimes a family member’s “job” is to care for the person with a disability in his/her own home, and is paid out of the consumer’s SSI check or other supplemental income.

Some parents have left their home to their son or daughter with a disability under a special trust in which money has been set aside to pay the taxes, upkeep, and insurance during the life of that individual, but the person essentially lives on his/her own or with personally paid support.

**It is not advised, however, that parents leave their home to a person with a disability unless the person is fully employed and/or financially and personally self-sufficient because the possession of certain assets will make them ineligible for SSI or Medicaid funded programs. (See Financial Concerns Section)**

### **HOMECHOICE**

A program to help persons with disabilities get mortgage loans, available in Jefferson County, emphasizes home ownership education and credit counseling as much as mortgage financing. HomeChoice makes it possible for someone with a disability – or the guardian or family of a disabled person – to get a mortgage loan by putting up as little as \$500 from their own resources. It is designed for people who otherwise could not qualify because of low income, lack of credit, or both. Fannie Mae, the nation’s largest source of financing for home mortgages is the source of this initiative, but the overall program is a joint undertaking of a coalition, Fannie Mae, Bank One, the Bluegrass Regional Mental Health-Mental Retardation Board, and 22 other public and private organizations. This group, called Kentucky Independent Home Ownership Coalition, hopes to attract 500 loan applicants in the first year. Loans are not subsidized under HomeChoice but borrowers can qualify with income other than a steady paycheck, such as Supplemental Security Income and seasonal wages, among others. To be eligible, borrowers must have a disability as defined in federal law under the Americans With Disabilities Act.

## RESIDENTIAL PROGRAMS AND HOUSING

Residential services are provided by a variety of governmental, for-profit and non-profit agencies. **Most residential programs have lengthy waiting lists. You must apply long before you actually need to move out on your own.** It is not unusual for people to be on a waiting list for several years or more.

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## Residential Resource List (taken from [www.councilonmr.org](http://www.councilonmr.org))

**Introduction:** The Council receives hundreds of calls each year requesting information about residential alternatives for children and adults who have mental retardation. Because residential services and supports are so individualized, it is difficult to respond to these calls with a simple list. We urge anyone receiving this information sheet to carefully consider all alternatives, to obtain additional information and materials from the service provider, and to visit any residential placement being considered.

Further, our experience indicates that often times people requesting residential information may really be wanting other types of assistance—for example, in home support, respite or babysitting services, regular and appropriate day or vocational programs, etc. If you are interested in any or all of these alternatives, please request information sheets from the Council. Finally, residential alternatives require much planning and decision-making. We encourage you to review the attached brochure before you begin calling the service providers listed below.

**Types of Residential Services:** There is a wide array of residential alternatives and providers in our community and state. Providers include the state, private non-profit agencies, and for-profit agencies. Some services provide large congregate living, while others provide small group homes, apartments, or even individual placements with a family, roommate, or paid staff. The matrix on the back of this sheet provides much of that information. The matrix, however, is simply the first step in the inquiry process.

### Major State Providers:

**Department for Social Services:** DSS provides services for dependent children and adults with disabilities. Services for children include special needs adoption, foster care, and specialized foster care. Services for adults with disabilities includes placement in personal care homes (1-3 persons or large congregate settings). Below is a listing of how to contact DSS:

Dept. for Social Services 908 West Broadway Louisville, KY 40203	Special Needs Adoption	595-3275	Adult Protective Services	595-4803
	Foster Care (Children)	595-4550	Child Protective Services	595-4803
	Intake & Info for Adults	595-4803	Personal Care Homes	595-4409
	Family & Personal Care	595-4409	Medicaid/Community Based Services	595-4260
	<b>Guardianship Services</b>	<b>595-4052</b>		

**Department for Health Services/State Facilities:** All applications for state operated facilities are processed by the MR/DD Office at Seven Counties Services: Call 459-5292. All of these facilities are large, congregate settings.

- Central State Hospital, ICF/MR Louisville, KY 502-245-4121 Primarily adults with moderate/severe MR/DD
- Hazelwood ICF/MR Facility Louisville, KY 502-361-2301 Primarily adults with severe/profound MR/DD
- Oakwood ICF/MR Facility Somerset, KY 606-679-4361 Children and adults with severe/moderate MR/DD
- Outwood ICF/MR Facility Dawson Springs, KY 502-797-3771 Primarily adults with severe/moderate MR/DD

**Private Residential Providers:** The following matrix includes information about many residential service providers within the state of Kentucky. For additional specific information about any of the residential programs listed below, please call the program directly. *(List not in alphabetical order)*

Name	Address	Telephone	Contact	Type	Size	Ages	Descriptors
Applepatch	7408A Hwy. 329 Crestwood, KY 40014	(502) 657-0103	Alan Boeschel, Program Services	Private Non-Profit	7	Adults	Group Home
<a href="#">Cedar Lake Lodge</a>	3001 Jerricho Road LaGrange, KY 40031	(502) 222-7157	Rebecca Martin	Private Non-Profit	76 beds	Adults	Licensed ICF/MR targets severe & profound MR/DD & those who require medical/nursing care
<a href="#">Cedar Lake Residences</a>	7984 New LaGrange Rd. Louisville, KY 40222	(502) 327-7706	Marina Netherton	Private Non-Profit	Today serves 65 Individuals	Adults	Apartments & duplex Off Site supervision
Kentucky Opportunities	12700 Shelbyville Rd., Suite 1000 Louisville, KY 40243	(502) 254-4200	Social Worker	Private Non-Profit	1-5 person placement	Adults and older teens	New provider in community
Community Alternatives	895 E. Main Street Frankfort, KY 40601	(502) 875-5777	Social Worker	Private For-Profit	1-3 person placement	Children and Adults	
Community Living, Inc.	333 Guthrie St., Suite 202 Louisville, KY 40202	(502) 585-5272	Steve Zaricki	Private Non-Profit	1-5 person placement	Children, teens, adults	Individual Family Placement or small group setting, SCL

<a href="#">Day Spring</a>	3421 Illinois Ave. 40213, and 1522 Baxter Ave. Lou. KY	Illinois Ave. Office (502) 636-5990	Social Worker 638-9420	Private Non-Profit	12-apartment complex, community homes. & group homes	Adults	24 hour staffed Residential programs in HUD subsidized housing
Dreams with Wings	1579 Bardstown Rd. Louisville, KY 40205	(502) 459-4647	Jenifer Frommeyer	Private For-Profit		Children and Adults	SCL
Higgins Learning Center	567 State Road, Hwy 141N Morganfield, KY 42437	(502) 389-0822	Social Worker	Private For-Profit	56 beds	Older teens & adults	
CAKY-KIPDA	4109 Bardstown Rd. Suite C Louisville, KY 40218	(502) 491-4001-8311	Social Worker	Private For-Profit	13 homes	Children and Adults	SCL
Panorama	980 Morgantown Rd. P.O. 1113 Bowling Green, KY 42101	(502) 782-9888	Social Worker	Private For-Profit	58 beds	11 years old and up	Serve moderate to profound MR/DD
Quest Farms	627 Glass Pike Georgetown, KY 40324	(502) 535-6064	Social Worker	Private Non-Profit	3 staffed group homes 6 persons each	Adults	
Res-Care (CAKY)	10140 Linn Station Road Louisville, KY 40223	(502) 394-2100	Social Worker	Private For-Profit	Supported Living, Group Homes, Large Facilities	Children & Adults	SCL
Harmony Habitat	P.O. Box 372 Bloomfield, KY 40008	(502) 252-0203	Peggy Kesler				
Stewart Home School	4200 Lawrenceburg Road Frankfort, KY 40601	(502) 227-4821	Social Worker	Private For-Profit	420 beds	Children & Adults	Mild to Severe MR/DD
Wendell Foster Center	815 Triplett Street P. O. Box 1668 Owensboro, KY 42302-	(502) 683-4517	Social Worker	Private Non-Profit	63 beds	Children & Adults	

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Some of the information in the section above is from the resource manual [Building Your Future](#) from Seven Counties Services. For more information about residential services, call Seven Counties at 502-459-5292 or 1-800-459-5292

## **GOVERNMENT-FUNDED SUPPORTED LIVING PROGRAMS**

### **SUPPORTS FOR COMMUNITY LIVING**

This program offers services to persons with mental retardation or developmental disabilities through a Kentucky Medicaid waiver. The waiver is called Supports for Community Living (SCL) and is administered by the Division of Mental Retardation. It was developed for Kentucky residents as an alternative to institutional care. **An important point to remember is that this waiver does not pay for residential expenses like rent or mortgage payments, but rather for residential services** called “residential supports” that pay for up to 24 hour supervision, and training in activities of independent living and self-care. It also stipulates that no more than three individuals receiving waiver services can live in any one residential setting. This program offers various types of support in the following areas:

- support coordination from a caseworker
- residential supports
- community habilitation
- supported employment
- community living supports
- behavior supports
- psychological services
- occupational therapy
- physical therapy
- speech therapy
- respite
- wellness monitoring
- personal emergency response system
- specialized medical equipment and supplies

Even if you are not sure if you will need these services, you should get information and apply as early as possible because there is a lengthy waiting list for this waiver under normal conditions of need. For a complete description of each of the supports and services listed above, visit the website at: <http://mhmr.chs.ky.gov/mr/scl/services.asp> or call the Division of Mental Retardation at 502-564-7702 for a hard copy.

**(This is a Medicaid funded waiver program administered through a complex application and validation process which will be described in detail in the Financial Concerns Section. The**

Application for SCL Waiver and ICF/MR Services form (called MAP-620) and SCL Waiting List Validation form are included at the end of Financial Concerns Section for your study. Become familiar with it in order to fully understand and protect the status and eligibility of your loved one.)

### **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 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 (funding comes from State General Funds) and is competitive. (See Financial Concerns Section for complete details)***

### **RENTAL AND OWNERSHIP HOUSING**

Rental and ownership housing programs are available under Section 8 rental assistance programs, public housing, and other assisted housing.

- Housing resource guides are available from the Kentucky Housing Corporation at (502) 564-7630.
- Section 8 renewal policy guidebook and other housing resource information is available online at <http://www.hud.gov/> or you may order a printed handbook by calling 1-800-767-7468.
- Public housing/section 8 housing choice vouchers are available in Kentucky at <http://www.hud.gov/local.lou/louphvacancies.html>
- Housing resource materials are available through the KY Division of Mental Health, (Housing Coordinator, Louis Kurtz) at 502-564-4448
- Kentucky Housing Corporation (Support Housing Specialist, Jim Sparks) at 502-564-7630, ext. 364
- Rural Housing Services (formerly Farmers Home Administration) 1-606-224-7300

- U.S. Department of Housing and Urban Development, Kentucky State Office  
<http://www.hud.gov/local/lou.index.html>

**(The information above was taken from Building Your Future, a resource manual prepared and published by Seven Counties Services. A complete copy may be obtained from their office at 3717 Taylorsville Road, Louisville, KY. 40220-1366.)**

### **QUALITY CARE CONSIDERATIONS**

1. Visit the homes in which you are interested with your family member and spend time there. Ask if it would be okay with residents if you came for a meal.
2. If serious about a residence, visit it at several different times during the day both when it is busy and during quieter times when it may be easier to talk with staff and residents.
3. The best source of information about the quality of supports an agency offers is the people who receive them. Find out if current residents and their families are willing to speak to you and ask several of them about their personal experiences.
4. Ask staff if they will visit and spend time with your family member with a disability so that they can get to know him or her. Observe the way staff members interact with your family member.
5. Talk with people at the “House Manager” level. Administrative staff is often distanced from what happens at individual homes.
6. Given the high turnover rates among direct support staff, find out how long a person has worked at a specific home prior to asking them to respond to your questions.
7. Think about what things are most important to you and your family member and let prospective agencies know that these are non-negotiable.
8. When asking questions to find out how the agency does things, use examples from your family member’s life. Ask staff how they would handle “real-life” situations that are likely to come up.
9. Keep track of whether the persons to whom you speak ask questions about the preferences and needs of your family member and the type of supports you desire.

(These questions and many other used throughout this guide are taken from a publication called, **“Through Asking the Right Questions....You Can Reach Your Destination”**, developed by the Research and Training Center on Community Living, Institute on Community Integration UAP, College of Education and Human Development, University of Minnesota and Developmental Disabilities Division, Hennepin County Social Services. It appears on the web at: <http://rtc.umn.edu/questions/>) or you can obtain a print version from the CMR Leadership Institute at 587-6500 while supplies last or order a print version from the publications office of the above by calling (612) 624-4512.)

### **QUALITY CARE INDICATOR QUESTIONS:**

1. How long has this agency supported persons with disabilities within community residences?
2. How many persons with disabilities does this agency serve and how long has it served this many individuals?
3. Would this agency consider setting up a home in a different part of the county or a different county, to meet the desires of particular residents of families?
4. How does this agency maintain its houses and make repairs to the property of the house?
5. How does this agency choose locations for houses and match people with housemates?
6. Have any of the homes this agency runs ever been cited for violations? If so, please describe them.
7. To whom do the houses where residents live belong? If they are leased, for how long do leases typically run?

### **FAMILY CARE AND PERSONAL CARE HOMES**

At the present time, Kentucky has around 90 “freestanding” licensed personal care homes, (freestanding means they are not part of a larger facility such as a nursing home); and it also has over 150 “family care” homes in which an operator is allowed to offer personal care to up to three residents in a private home. Medicaid does not pay for personal care or family care homes, but the state will help low-income people pay for their care. The resident generally contributes monthly income such as Social Security or disability check, and the state pays the rest.

Personal Care Homes are licensed by the state and inspected annually but many advocates are surprised to discover how lightly regulated personal care homes are compared to nursing homes which must meet an array of federal and state standards. For example, regulations do not require nurses to be on staff at personal care homes. They require that personal care homes provide in-service training to employees but don't specify the type of training. The Kentucky Board of Nursing has long been concerned about whether personal care workers have adequate training to dispense medicine and give CPR. State regulations for personal care home do not require that staff be certified in CPR.

### **LETTING GO: POINTS FOR PARENTS TO PONDER**

Letting go of children when they become adults is a multi-stage process that at best is a tar pit of sticky negotiations. Even when we believe our adult children to be fully able, there are so many strings attached that the cutting of them takes years before our relationships become adult to adult rather than parent to child (if that ever really happens!)

And as part of the typical relationship, every child comes with a gigantic guilt package attached, one that hangs over your head whenever anything is not going well for him/her. As you well know, the guilt package that comes with a child who has a disability has a capital G. Many years have been spent in questioning our every action before and after their birth, throughout their childhood and adolescence. So, when you are the parents of an adult with disabilities - a person you have worried about, felt inadequate to take care of and protected his/her entire life, the complications are one hundred fold.



Let's face it, no one will ever take care of your son or daughter the way you do. You will have to accept that and get over it. If you keep looking for those standards of care elsewhere, you will never be satisfied. Our adult children really can adapt. They will grow up and they will survive and most likely be happy even without our managing every minute of their lives; maybe even because we aren't doing that anymore.

You probably feel that your loved one is so much more vulnerable than the typical adult and does not come close to having the skills for independent living. And in many areas of life's competencies you may certainly be right. The point is, however, **how will they learn life skills when we do everything for them in our homes? Let's make it a resolution, (just as we do with our other child/children), to never do for our loved one with a disability what he/she can do for him/herself!**

Have you ever really looked at a list from experts like the authors of "Transitioning to Independence: Challenges for Young People with Disabilities and their Caregivers"? Look back to the Transition Section of this manual. There are at least 13 areas of competencies with about 10 sub-skills under each area. O.K., you are saying that not even you have all those skills! But **you** can learn them if you really need to – but can your loved one learn them from you? Are you planning for his/her transition to adulthood? Are you systematically teaching your loved one any of the multitude of competencies beyond some self-care skills?

**The bottom line is, we are not doing our adult children any favor by doing everything for them and protecting them from frustration and failure? And isn't doing everything for them a way to protect ourselves because we don't have the patience and know-how to do the hard work of teaching them and asking them to practice or letting them practice real life skills? Won't the biggest**

**disservice of all be when we die without having planned for another safe and secure place for our loved one to live? DON'T WAIT FOR A CRISIS!**

Do plan for their future while you are still healthy and able. What would really be devastating for our children is for them to see us have a stroke or collapse and be left without a support system to help them continue their lives without us. You don't really mean for that to happen but it might if you don't make plans now. So take the advice of a survivor of the experience of having a young adult who needs total assistance with everyday care and activities move out of our home to a 24 hour staffed residence. Say to yourself: **THIS IS NOT ABOUT ME, THIS IS ABOUT AN ADULT WHO NEEDS A LIFE AND A HOME OF HER/HIS OWN.**

Plan for the next part of your child's adult life while you are still here to support him/her to look for another home by visiting different residential settings. Your child will need you to fill out applications, explore and then make the necessary financial arrangements. **Help them make the move while you are here to support them emotionally and physically in the transition to their "own home", and while you are sharp enough mentally to personally oversee their care for years to come.**

**WE ARE NOT SAYING IT WON'T BE HARD**

As if the physical, financial, and practical arrangements weren't enough, the most difficult adjustment may be emotional and psychological. As parents of loved ones whose every need often had to be fulfilled by a parent or family member, it is no wonder that we have perhaps become co-dependent. Now don't get mad! Being needed can be very satisfying and addictive at the same time that it is maddening and terrifying. What would our lives be like without the constant care of our loved one? What would we talk about, what would we focus on? Believe me, you will still be very involved in his/her life when your son or daughter moves into some other living arrangement, but the absence of that person in your home will take a big emotional adjustment.

Jackie Marquette, from Fern Creek in Louisville, is an advocate for increasing independent living for individuals and their families. She has written a book called **Independence Bound** about her son who has autism and their journey to an independent life for Trent. Here are her ten critical questions a family must ask themselves to develop a new perspective toward independence.

- Have I estimated my family's change carefully and identified who is likely to lose what – including what I am likely to lose?
- Have I defined clearly what is over for my family, my son, and for me?
- How will I acknowledge these losses with sympathy?
- Have I permitted my family members, including our child with a disability, to grieve?
- Have I expressed my own sense of loss?

- Have I defined clearly what is not over and what is the same for my family, my daughter, and myself?
- Have I found ways to mark this transition for our child and our family?
- Have I made a plan for giving my family and each family member a piece of the past to take with them?
- Have I made it clear how the ending we are making is necessary to protect the family or conditions on which our family depends?

It takes a lot of courage to do the right, best thing for our loved ones. Now take a deep breath.....and let go.

**(Independence Bound** can be purchased by contacting Harmony House Publishers, P.O. Box 90, Prospect, Ky. 40059 or by calling 1-800-809-9334. Jackie can be reached through her website at [www.Independencebound.com](http://www.Independencebound.com) or through Email: [Jam4independence@aol.com](mailto:Jam4independence@aol.com))

**VOICE OF EXPERIENCE: We asked Ray Goodman, “What would you say are the ten most important things you would tell someone who is going to move away from home?”**

*“First I would tell someone who is looking for a place of their own to start by being more independent and do the things you can do yourself and get your family support. Be more responsible to prove that you can live on your own. Then I would tell them to look at different apartments, find out what’s around it. I would make sure it is on a bus line and near a Kroger and Target or Walmart. Be sure to have someone who will check up on you like twice a week. When you are on your own you can call friends on the phone and go places like to the movies or go on vacation with them or have a girlfriend or boyfriend over for dinner. The important thing is to prove and show that I am a person who can live on my own.”*

### **VISION: YOUR OWN “HOME” AND COMMUNITY INCLUSION**

So the **vision** is that you will live by yourself or with the person of your choice in the home of your choice with the supports needed to be a responsible and successful homeowner or renter. **And that you will participate in life’s activities as a valued member of your community.** All developers of person-centered planning have emphasized that we should think about the life of a particular person not as an individual, but as a community member. **Remember, to be independent is important, but to be interdependent is essential!** The original “circles of friends” in personal futures planning were composed of community friends of a person, not staff. These original circles were designed to free people from services to lives they wanted in community with their needs met in large part by that circle of support. We need to move the perception of ordinary citizens from the belief that it takes a “special person” to work with “those people” and that only formal support systems are responsible for people with

disabilities. Every “ordinary” person has the capacity to accept, befriend, support and value the person with disabilities as a contributing member of their community.

### **REALITY**

The unfortunate reality is that many, many adults with disabilities at the present time are not even able to leave their parents' home much less live in the community. After graduating or leaving high school, services for the adult with disabilities will no longer be mandated under any law. So the **reality** is that unless you live with your parents (and even then you may need other financial support), **funding availability and the adult service system determine whether or not you will receive services. Resources are very limited, and this makes it extremely important for families to plan and advocate for expanded residential placement opportunities.** Many, many individuals in Kentucky are still living with parents into their own 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.** There is no doubt that a crisis is in the making with the death of the parent if no planning has been done and no government support is available. (See more details in the Financial Concerns Section.)

### **THE ROLE OF COMMUNITY**

Even for those fortunate enough to have community services in residential placements outside their family home, the unfortunate situation is that some individuals with disabilities may be living in homes or working in ordinary jobs, but are still lonely and socially isolated. Some service provider agencies make an effort to help people have friends who are ordinary community members, join local organizations, and get to know neighbors. However, **these efforts can only go so far without the involvement of the community itself. It must be in the mind-set of community members (including faith communities) to fully include each and every person as a community member.** Until communities play an active role in this goal, the dream of person-centered services will never be completely realized.

### **ADVOCACY NEEDS:**

1. Although great strides were made in 2000 with the passage of House Bill 144, the funding and future funding promises will not catch up with the estimated 8,000 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 services for persons with disabilities and it can not make up for 30 years of fiscal neglect with one legislative action. **The needs of individuals for the Supports for Community Living Waiver still far outweigh the funds available. The current waiting list is over 2000.**

2. Even with the recent increase in funding and the resulting increase in allocated “slots” to the Supports for Community Living Waiver, many persons with disabilities will be in the strange position of finally having funding to buy services but with no services available to buy. The Division of Mental Retardation staff is encouraging new providers to open up residential and other services in Kentucky. But with the 3 year rate “freeze” and the new flat rate for services across the state which reimburses Jefferson County SCL providers at a rate (for many) that is under their actual cost, many present SCL providers are becoming discouraged, and few new providers want to face the financial hardship that such a flat rate system enforces. When hearings are held on this matter, we must all show up in Frankfort and support our provider agencies. To find out when these important events are occurring, be sure to get on mailing list for the Coalition for Quality and Choice by calling the Council at 584-1239 and giving your name, address, and phone number for the telephone tree.
  
3. This financial disaster has the result of putting persons with high intensity needs, behavioral problems, or dual diagnosis in real jeopardy. When an agency serves a person whose needs are so great that the staff needs special training and the staff-to-client ratio has to be increased, then costs go up. Since the present reimbursement is already below actual cost for many providers, how can they be expected to extend themselves even further into debt. This flat rate has resulted in discriminatory treatment of persons with high intensity needs. If your family member has been refused services because of their needs, please call the Council on Mental Retardation and speak to Donovan Fornwalt about your situation. Then when hearings are held in Frankfort, be there to tell your story. (See Advocacy Section for further details.)