
Self Advocacy / Advocacy

Advocating for Change

Introduction

The history of the disability movement is filled with examples of advocacy: individual advocacy, group advocacy and systems advocacy. The resulting social changes have enabled people with disabilities to access education and vocational programs, enter the work force, and live in their home communities along side their non-disabled peers. People with disabilities are increasingly seeking to speak on their own behalf, to control their lives, and to be a participating member of their community.

Historically, parents, families and advocates have given voice to advocacy issues. Parent and family advocates fought for free appropriate education for their children, for access to vocational programs, and access to community programs. Persons with disabilities, often called self-advocates, joined parents and families in working for the passage of the Americans with Disabilities Act in 1990.

Advocacy is a problem- solving process used to bring about social change:

1. To protect rights or change unfair discriminatory or abusive treatment to fair, equal, and humane treatment.
2. To improve services, gain eligibility for services or change the amount or quality of services to better meet the needs of an individual.



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3. To remove barriers which prevent full access to full participation in community life.

Advocacy, or speaking out on behalf of an individual, a group of individuals, and/or a cause, is a tool used by citizens in our democracy to bring about changes and improvements. Advocacy can be carried out by an “advocate” (a person who speaks for others or helps others speak for themselves) or a “self-advocate” (a person with a developmental disability). A self-advocate may speak out about a personal need or the needs of an entire group of people with disabilities. Advocates and self-advocates often work together to bring about important changes.

In this section, we will discuss (1) individual advocacy (advocacy on behalf of one person with a disability) and (2) systems or class advocacy (advocacy on behalf of an entire group or class of persons with disabilities), as well as (3) how to be an effective advocate for change.

- ✓ **Advocacy 101**
- ✓ **Self-Advocacy**
- ✓ **Basic Steps in Advocacy**
- ✓ **Advocacy Strategies**
- ✓ **Advocacy Resources**

Advocacy 101

Definitions: Defining the various types of advocacy and understanding who is involved in advocacy is an important first step. Below you will find a number of common definitions for various forms of advocacy.

Individual Advocacy: Individual advocacy is when a person or a group of persons “speak out” on behalf of **one individual**. The person or persons speaking out can be a parent, family member, friend, neighbor, and/or the persons with the disability. Individual advocacy often revolves helping an individual gain access to a needed program, assuring an individual's rights are not infringed upon, and/or making sure a person with a disability is treated fairly and respectfully.

Group Advocacy: Group advocacy is when a person or a group of persons “speak out” on behalf of a **group of persons** with disabilities. Often times the group will have similar needs or problems. For example, an employer may not be paying a group of persons with disabilities fairly, a group of persons with mental retardation may be denied admission to a local recreation center, or people with physical disabilities cannot eat in a local restaurant because it is inaccessible. Again, the person or persons speaking out can be a parent, family

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member, friend, neighbor, and/or the person with a disability, but, in this case, they are speaking out for a group of similarly situated individuals with disabilities, not just one person.

Class Advocacy: Class advocacy is when a person or group of persons speak out on behalf of **an entire class of people**. For example, the state of Pennsylvania was sued on behalf of all people living in state institutions, advocates successfully fought for the passage of PL94:142 which mandated a free public school education for all children with disabilities, and advocates worked hard for the passage of Americans with Disabilities Act, which provides protections to all people with disabilities. Generally class advocacy is done by a group of advocates including persons with disabilities, parents, families, friends, neighbors, professionals, attorneys, and others interested in the disability issues.

Self Advocacy: Self-advocacy is a process in which people or groups of **people with disabilities** speak out on their own behalf. Speaking out on issues of importance to an individual is called "Individual Self-Advocacy, while speaking out as a group of like-minded individuals is called "Group" or "class self-advocacy." These definitions are the same as those noted above. The only difference is in who is doing the advocacy—in the case of self-advocacy, it is the consumer or consumers with disabilities rather than parents, family, friends, and/or advocates.

Bonnie Shoultz in her article *More Thoughts on Self Advocacy: The movement, The group, and the Individual* defines the self-advocacy movement as an international civil rights movement led by and for people with developmental disabilities and is one part of the broader disability rights/independent living movement. It is about improving the civil rights of people who have been and still are disenfranchised (oppressed, ignored, devalued, and segregated) because of how they are viewed as people who have or are labeled as having developmental disabilities.

The self-advocacy movement is teaching people with developmental disabilities, especially movement members, about their rights and responsibilities as citizens of a society. Members learn ways of understanding and working to correct injustices done them, and learn positive ways of directing their feelings of anger when they feel oppressed. Movements leaders and members exercise their influence in the broader society by meeting with service providers and asking for change, by training employees and family members, by testifying at public hearings and legislative sessions, by writing letter and attending rallies, by participating on committees, and in countless other ways.



The Voice of Experience: Susan Scott, Self-Advocate

I helped start a chapter of People First, a self-advocacy group, in Cincinnati, Ohio and was active in it for 4 years. I learned how to speak up for myself. If I don't speak up for myself no one will understand what I need. Since leaving Cincinnati I have been attending trainings and making presentations on self-advocacy.

There are growing numbers of self-advocacy groups through the country and world. On August 2, 1991, over 800 self-advocates from across the United States and Canada meet in Nashville for the second North American People First Conference. The excitement was high as self-advocates voted to start a national self-advocacy organization. It was decided to divide the country into 9 regions and elect regional representatives to further develop the organization. Representatives meet 4 times a year. The association is now called S.A.B.E Self Advocates Becoming Empowered.

In August 2003, Kentucky Self-Advocates for Freedom was organized as the statewide association. The organization is directed by Kentuckians with disabilities committed to working in partnership with all interested parties to promote equal rights, inclusion, self-advocacy, support and education in all realms of life.

To get information about, or to join Kentucky Self-Advocates for Freedom contact: Kentucky Self-Advocates for Freedom at 800-525-7746 or 502-937-6894.

Local Self-Advocacy groups are being formed in many Kentucky communities. The groups will support the work of the Kentucky Self-Advocates for Freedom as well as work on local issues in their own community. To date, Kentucky has six local groups. To get information about, or join a local Self-Advocacy group in Louisville, contact: Rhonda Logsdon at 502-937-6894 or Beth Richardson at 502-587-6500.

Why Self-Advocacy: Many people with disabilities want to increase the amount of decision-making and control they have in their own lives. For some people it is developing the self-esteem and skills necessary to begin making relatively small choices in their lives (e.g. selecting their own clothes, determining what movie to see, talking with a program supervisor about needed changes in their jobs, etc.) For others it may mean determining where to live, selecting a roommate, changing jobs, or handling their own paycheck. The phrase sometimes used to describe this is "self-determination." Self-determination means that with supports persons with disabilities are increasingly able to make

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decisions and choices that impact their lives. The amount of support and assistance a person with disabilities needs to make such decisions and choices is highly individualized. Self-determination without the necessary supports will not be effective in assuring the best opportunities for persons with disabilities. In addition to a flexible and funded support network, there must be a public policy foundation to strengthen and enhance the self-determination movement.

Historical View: Advocacy can focus on local, state, and national issues. Initially many individuals and small groups of advocates focus on local issues of importance to them (e.g. access transportation, local funding for programs for persons with disabilities, positions on local boards and public committees). These local efforts often lead to work at a state or national level. As advocacy skills and experience increase, so do opportunities to influence the issues facing persons with disabilities. The national ARC (formerly the National Association of Retarded Citizens) grew out of a grassroots movement in many communities during the early 1950's. The Council on Mental Retardation in Louisville is an example of such a local grassroots movement. The Council was instrumental in establishing the Kentucky ARC, and provided some leadership in the national ARC.

There is no single way to successfully advocate. Each individual and group will have its own strategy—what works best for the person or group, what is most comfortable, available people and financial resources, and what goal is being sought. There are a number of strategies including letter writing, phone calls, rallies, coalitions or groups of like minded people, action research, and direct lobbying. The method used will depend in large part on the goals and target of the advocacy issue.

Basic Steps in Advocacy:

The following are the basic steps of advocacy as outlined by the Center for Community Change, a nationally recognized organization that assists people to build better communities and policies.

- Identifying and building a constituency
- Identifying an issue
- Defining the target
- Generating calls and letters
- Organizing actions and demonstrations
- Meeting with legislators

Identifying and building a constituency: The most successful advocacy movements have achieved their success because they were mass movements grounded in disciplined organizations with large numbers of people who had a

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direct self-interest in the issue. Examples of such movements include environmental groups, the civil rights movement, passage of federal disability laws (PL94:142, IDEA and the Americans with Disabilities Act).

There is no substitute for voting, or the hard work of organizing a group of like-minded people. Organizing requires building a membership from the ground up, developing issues that matter to people, and launching campaigns to address these issues that are directed and controlled by the group or constituency.

Identifying an Issue: There are lots of problems that you may care about, but not all of them are issues that you or your organization can or should take on.

People with disabilities have many issues. The trick for an individual self-advocate, advocates or a group of self-advocates is to decide which issues to work on first—to establish priorities.

Think it through, and then make a decision.

An issue is a problem around which a community can be organized. The issue should be immediate, specific and realizable as defined by Stan Holt, the Director of People Acting through Community Effort (PACE).

- “*Immediate*” involves either the benefit folks would get from victory or, preferably, the harm they would suffer from inaction.
- “*Specific*” refers to both the problem and its solution.
- “*Realizable*” refers to how achievable is the victory.

To choose an issue you must determine whether an issue can be won. Ask yourself:

- *Who is affected by the problem, and can we get to them?*
- *How much does the problem hurt them, and how hard are they likely to fight?*
- *Are they able to escape easily, or is standing and fighting their only option?*
- *What resources are we likely to need and where can we get them?*

Then you need to think about the other people and organizations that need to be involved in the solution. Ask yourself:

- *Who benefits from the way things are, and how much?*

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- *Could they easily give us what we want, or would it cost them, and how much?*
- *How would the solution we seek change this equation?*
- *Could we go after something that would help us just as much, but get us more friends?*

Think big, but think it through. Remember, however, eventually you have to choose an issue and act!

If you are part of an organization, such as a self-advocacy group, you need to ask more questions, including:

Could our members be hurt or helped by what's proposed?

- *Do your members have direct experience with this issue?*
- *Could your organization and its work be hurt or helped?*
- *Can you make a difference if you get involved?*
- *Do you have a legislator on a key committee for this issue?*
- *Can you show what the outcome can do for people in their districts?*

Defining the target: Once you have identified your issues, the next step is to identify the target of your advocacy campaign. In some cases, this will be fairly obvious. For example, if you are trying to stop Medicaid cuts at the state level, you'll have to go after your representatives and senators on the state and federal level. In other cases, you may have many options—perhaps a state agency or city officials or a local provider.

Once you have identified your target or targets, the next step is to get them to do what you want them to do. This is not as simple as it may sound—a little up-front investigation can save a lot of grief later.

Let's go back to our example – Medicaid cuts.

Try to answer several questions:

- *How can we really move the targets?*
- *What are their political bases?*
- *Were their last elections close?*
- *Did they win because of poor and minority voters or, conversely, because voters stayed home?*
- *Have they responded to our group in the past?*

In short: what will it take to get others to join us and to champion our cause? In thinking through these questions, you'll sometimes want to expand your constituency—for example, if a Congressman is especially responsible to organized labor, it probably makes sense to build some relationship with local unions. Or, if you don't have many members in a key part of his or her district, you might want to join with groups (or individuals) in that area who share your concern. Many groups have found that some issues provide opportunities to increase allies and members. Seek help as you build your power base. It is important, however, in building coalitions and alliances to always frame the issue from your perspective.

One of the important considerations in defining your target and building constituencies is to think about the long-term impact of your message. In deciding which issues to pursue, some groups have created two or three tiers of possible action:

1. Issues to which they make a major commitment,
2. Issues to which they agree to monitor and make their voices heard when needed, and
3. Issues to which they will simply show their support by joining a sign-on letter.

You cannot organize a press conference or letter writing campaign on every issue. You want to communicate only when you care enough about an issue that it might affect your own well-being, the basic rights of disabled people, or the way you vote in the next election.

Generating calls and letters and organizing actions and demonstrations:

Now it is time to begin taking action. You have your issue. You have your allies. You have the target(s). Now it is time to take action. Your action activities may include:



- Writing letters and post cards to key people
- Establishing telephone and fax trees
- Creating a sample email and sending it to friends, members and allies
- Setting up tables and distributing flyers in areas that reach the people affected by your campaign
- Planning a door-to-door canvassing
- Organizing a rally or demonstration
- Meeting with legislators
- Making media and communications part of your overall work plan.

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- Testifying at a public hearing
- Hiring or working with a lobbyist
- Researching issues and using relevant data
- Writing and calling policy makers
- Writing letters to the editor of your local newspaper
- Knowing your issue and talking about it to friends, neighbors and acquaintances
- Working on local and state political campaigns
- Working with like-minded people

Meeting with legislators: There are a number of important guidelines to consider when meeting with legislators.

- Take several people—a diverse group—people affected by a particular issue or policy.
- Make sure you're meeting the right person. Ideally, talk directly to the legislator. If that's not possible, make sure you talk with the staff person assigned to your issue. For example, most legislators have a staff person assigned to health care/long term care. If you have Medicaid concerns then you should talk with that staff person.
- Know the staffers who work for your representative. Your representative has two sets of staff: local or district staff, and Washington, DC staff, on Capitol Hill. In general, a representative's district staff is best used to get access to the member, or to solve local problems.
- Take the time to introduce yourself to the legislative member. Describe whom you represent, your membership, what you do and your accomplishments.
- Make your visits with specific requests. Never leave a meeting without commitments and deadlines.

Recently legislative advocacy has taken on some special challenges. At every level of government, there has been a dramatic conservative turn. While much of our collective activity has focused on defending or holding on to what we've got, it is still possible to score some victories. The best example of this might be the increase funding of community-based programs for people with mental retardation during extremely tight budget times. Keep the following things in mind.

- ✓ Don't assume your representative is "a lost cause."
- ✓ Think about how your agenda could be expressed in conservative language.
- ✓ Don't assume that your representative knows anything about the programs you care about.

Take time to educate your legislators and help them understand your experience and your perspective. Give people the opportunity to do the right thing.

There are a number of additional strategies that are important to remember:

- **Voting: Tip the balance with votes from people with disabilities and their families.** People with disabilities and their families represent an untapped pool of votes. The key to good voter work is not just registering people to vote but to involve them in the process that includes educating them about issues. When politicians see people being mobilized to vote, it impacts their decisions. There is much you and your organization can do to interest people in an election and educate them about your issues. But remember when it comes to legislative officials: the votes are important.
- **Media and communications:** As stated above, make communications part of your overall work plan. Find ways to tell your story to a wide variety of journalists and think what would make it appeal to TV cameras.
- **Lobbying:** Lobbying can be a useful tool to achieve legislative success. Unfortunately, many groups cannot afford and/or are afraid to utilize a lobbyist. It is, however, a strategy that can make a major difference.

"10 Pillars of Successful Lobbying" by The Kentucky Gazette

The Kentucky Gazette staff has spent years studying the legislative process and how lobbyists work effectively with members of government. There are 10 categories that define the elements of lobbying. They are:

One: Accept the politics. People in business find out what the public wants and gives it to them. Legislators do the same.

Two: Be a credible source of trusted information. Credibility is your expertise. Trust is how others see your intentions.

Three: Know the players. Who's what decides what's what. Get to know the leaders and their staffs. Make sure they know you.

Four: Lobby where they live. Lobbying is performed on- the- spot in the Capitol and through grassroots organizations at home.

Five: Build a bond. When you build a bond based on shared values, communication is easy, friendly and frequent.

Six: Navigate through bigger issues. Be aware of the bills and amendments that dominate the time and mood of legislators

Seven: Know the ropes. Understand the steps in the passage of a bill and what you can do to assist or ambush it at the next step.

Eight: Shoot, scoot and communicate. Success depends on the distribution of information to legislators and their constituents.

Nine: Be right and be in season. Match the values of society and the mood of legislators. Get involved early, before positions are frozen.

Ten: Common errors and survival tips. If you don't watch your step, Nos. 1-9 won't matter

Systemic Change: The following article describes a multi-strategic approach to advocacy. This is another important advocacy strategy.

***Common Virtue, Common Sense and Uncommon Effort
Strategies for promoting systemic Change***

By Donovan A. Fornwalt
Director of Government Affairs,
The Council on Mental Retardation

Purpose: To describe how any attempt to create systemic and substantial change requires multiple strategies.

In our effort to build a unique and effective coalition centered around the needs of people with mental retardation, we discovered some basic strategies. I will describe each of these strategies in some detail, relying mostly on direct experience to flesh out their meaning. Individual advocacy goals can also benefit from application of these strategies and principles.

If you are simply overcoming a temporary crisis, then maybe one or two of these strategies will suffice. In Kentucky we tackled an ambitious agenda, an immediate crisis, a history of fiscal neglect and a history of personal and professional infighting. All of these competing contests conspired to demand an uncommon degree of conviction and effort. These trying times and three decades of near absolute failure made it necessary to be very pragmatic, to set aside differences and to insist upon accountability from ourselves and our elected officials.

The Coalition for Quality and Choice was born out of the hearts and minds of a few people who care for and about people with mental retardation.

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These ordinary folks of common virtue and common sense thrust into a situation that made them feel powerless, cynical, apathetic, enraged and mostly fearful. I still do not fully understand how all this fear and apathy evolved into a political force and a rousing success.

While timing, historical context, will power and personality are all partial explanations; these are not things that we can control and replicate. What I have done is recognize some key strategies, activities and mindsets that formed a common thread in those years (1998 –2000) in Kentucky.

My sincere hope is that any dedicated group of people, people of common virtue and common sense, can apply these strategies and realize their dreams of inclusion, dignity, freedom and security for all people with disabilities.

System wide Change: A Multi-Strategic Approach

1. Public Education

- Selling civic duty or conscience
- Media is a Partner

Implicit expectation "to do something" (leadership vacuum) If the media is engaged consistently (especially major newspapers) then leaders are compelled to pay attention and your issue is assumed to be a major public policy issue.

- **Engage the media** *(Get to know the beat reporters, generate editorials, press releases and lots of phone calls to assignment editors.)*
- **Mobilize people** *(Don't do it alone. Energize parents, family, friends to make calls and write letters.)*
- **Direct & Broaden Understanding**
(Always teach. Give reporters the rest of the story. Stay on message. Have sound bites and human interest angles ready. User-friendly compelling research helps)
- **Be aggressive, thoughtful and deliberate**
- **Create your own media**
(Brochures, Press Conference, post cards, yard signs)

2. Lobbying Legislative Branch

- Missing piece for many non-profits, activists
- Tenacity, knowledge, tact, firm convictions, humility
- Select a lead Lobbyist

(If your issue needs legislative remedies then choose a leader that fairly represents the principles of the group, knows the legislative process, and is known by legislators & their staff. Must have the character traits listed above.)

3. Administrative Negotiation

- KY Governor frames most debates
- Secretary of the Cabinet for Health Services
(*Implements Governor's agenda*)
Get their attention early and often. Take note of public comments. Use their rhetoric ("the disabled are our top priority") in your materials, public testimonies and with media contacts. Stay on task on message
- Tact, careful pragmatic consideration given to
MESSAGE, METHODS, MISSION
- Respectful application of pressure (*Governor, Cabinet leaders, Legislators all need to save face. Remember, in politics there are no permanent friends and no permanent enemies. Be eternally pragmatic and courteous*).

4 & 5. Grassroots Support & Coalition Building

- **The Central Moment:** Make a collective decision to **set aside ideological differences**. We all have common bonds as parents and people who belong to the disability community. Ideology can divide and rarely changes minds and (on its own) never creates a genuine change of heart. That revolution of the spirit requires a humble surrender of ideology in favor of acknowledging kinship and the desire to improve the circumstances of all people with disabilities and their families.
- A short publication that describes the evolution of a successful statewide coalition, The Coalition for Quality & Choice, is available upon request from The Council on Mental Retardation, Inc. Call for your copy at 502-584-1239, ext.16. Ask for: **United We Stand: A Case Study of Empowerment To Bring About Social Change on Behalf of People with Mental Retardation in Kentucky 1998-2000.**
- **Any policy maker who fails to give considerable deference to the wisdom of a loving parent is making a mistake.** This is the sort of message that has universal appeal. It is fundamentally true. It is appealing to the grassroots. It is an effective media sound bite. And it gives political leaders something to ponder.
- Transcend ideology and embrace the needs of people.
- Translate individual fear and isolation into **group action**.

- Coalition members become “Ambassadors of Faith”
An initial leap of faith recognizes a truism that people of common virtue and common sense know intuitively and that is: Most parents struggle to do what’s best for their children.
- **Redefining the Problem:** Placing responsibility where it belongs. Political leaders must be held accountable for ignoring the needs of people with disabilities. Infighting is a distraction and it lets elected officials and bureaucrats off the hook. Moral imperatives can become political imperatives when people build effective coalitions.

Note: These are 5 of 6 strategies necessary to achieve advocacy goals, the sixth (litigation) may prove more necessary depending on the state and its history of advocacy.

Advocacy is a noble and exciting activity. It is an opportunity for everyone to stand up for what they believe and to support others in achieving their dreams. It requires a strong heart, an understanding of right and wrong, and a willingness to work long and hard. It is not for the faint of heart, but the successes (big or small) make an important difference in the lives of people with disabilities.

LEGISLATOR INFORMATION

It is always important to let your legislators know your thoughts about programs and services as well as your thoughts about future services.

Contact Information:

State Legislators:

- To find out who the state senator and representative is for your district or to locate contact information for your specific state legislators call 1-888-868-3762 or go to website www.vote-smart.org
- Visit the state's website for a complete listing of all Kentucky legislators at <http://www.LRC.state.ky.us/whoswho/whoswho.htm>
- Contact individual legislators at (502) 564-8100 or you can call the toll free Message Line 1-800-372-7181 and leave a message. Fax messages can be sent to (502) 564-6543

United States Congress

- To locate contact information for your specific United States representatives and senators go to the above vote-smart website
- For complete local and Washington addresses, phone numbers and current committee appointments, go to <http://www.lwvky.org/delegation.htm>

Advocacy Organizations

Name	Address	Phone
ARC—Kentucky	833 E. Main Street Frankfort, KY 40601	(502) 875-5225
Center for Accessible Living	981 S. 3rd Street, Suite 102 Louisville, KY 40203	(502) 589-6620
Cerebral-Palsy KIDS Center	982 Eastern Parkway Louisville, KY 40217	(502) 635-6397
Council on Mental Retardation	1146 S. 3rd Street Louisville, KY 40203	(502) 584-1239
Client Assistance Program, Dept. for Vocational Rehabilitation	209 St. Clair Street, 5th Floor Frankfort, KY 40601	(800) 633-6283
Down Syndrome of Louisville	1939 Goldsmith Lane, Suite 208 Louisville, KY 40218	(502) 635-6397
Epilepsy Association of Greater Louisville	501 E. Broadway Suite 110 Louisville, KY 40202	(502) 584-8817
FIND of Louisville	1146 South Third Street Louisville, KY 40203	(502) 584-1230
Kentucky Autism Training Center	571 South Floyd Street Louisville, KY 40202	(502) 852-4631
Kentucky Department for Protection and Advocacy	100 Fair Oaks Lane Third Floor Frankfort, KY 40601	(800) 372-2988
Kentucky Disabilities Coalition	P.O. Box 1589 Frankfort, KY 40602	(502) 875-1871
Special Parent Involvement Network KYSPIN	10301-B Deering Road Louisville, KY 40272	(502) 937-6894 (800) 525-7746
Mental Health Association of Kentucky	120 Sears Avenue Louisville, KY 40207	(502) 893-0460
Multi-County Client Council (benefits advocacy, affiliated w/Legal Aid Society)	425 W. Muhammad Ali Blvd. Suite 202 Louisville, KY 40202	(502) 584-1254, ext. 212
Parent Outreach	1146 South Third Street Louisville, KY 40203	(502) 584-1239
Prader Willie Kentucky Association	9213 Reigate Court Louisville, KY 40222	(502) 339-8782
Spina Bifida Association of Kentucky	982 Eastern Parkway Louisville, KY 40217	(502) 637-7363
Visually Impaired Preschool Services	1229 Garvin Place Louisville, KY 40203	(502) 636-3207