

**Charlotte Gaylor– Community Living**

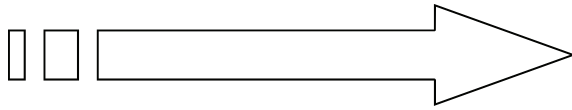


# **SPEAK MANUAL**

A Guide for Direct Support Professionals.



## Contact Information:



### **Seven Counties Services, Inc.**

3717 Taylorsville Road

Louisville, Kentucky 40220

(502) 459-5292 (telephone)

(502) 452-9079 (fax)

Sandra Mlinarcik PhD, Vice President and SPEAK Project Director

Jeff King, SPEAK Project Coordinator

Electronic mail: [jking@sevencounties.org](mailto:jking@sevencounties.org)

### **CMR Leadership Institute**

101 Witherspoon Street

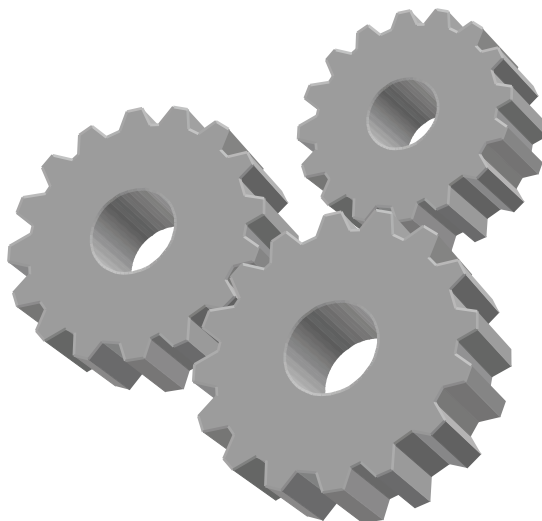
Louisville, Kentucky 40202

502-587-6500 (telephone)

502-587-6570 (fax)

Beth Richardson M.Ed, Director of the CMR Leadership Institute

Electronic mail: [brichardson@councilonmr.org](mailto:brichardson@councilonmr.org)



**SPEAK** is a three year project funded through the Center for Medicare and Medicaid Services. Responding to factors that contribute to high employee turnover, SPEAK enhances employment relationships through pre-service orientation; an apprenticeship period; membership in a regional professional assistance association; connection to a broad array of community supports; approved, paid leave; and regional collaboration on behalf of Direct Support Professionals (DSPs).



## Welcome

If you are a newly hired Direct Support Professional (DSP) you are about to discover how essential you are in the life of a person with a disability who wants to be as self-reliant as possible. As a DSP you provide guidance and support to a wide range of individuals, including people with physical, psychiatric or cognitive disabilities or chronic illness; children and youth who are at risk; and families who need assistance in supporting family members. Direct Support is a profession that demands complex skills and knowledge, ethical judgment and the ability to create long-term relationships of trust and mutual respect.



DSPs are found in hundreds of different settings with various job titles including Residential Counselor or Facilitator, Employment Specialist, Family Advocate and Personal Support Assistant. Many of these jobs share similar requirements and approaches including the ability to teach life skills, provide physical assistance, and to support the empowerment, choices and self-direction of the individual receiving supports. It is estimated that there are over 2 million Americans working in these roles. *(Note: much of the above text is excerpted from the NADSP fact sheet: The Direct Support Workforce by Marianne Taylor, Human Services Research Institute).*

## Forward

This Guide was developed for you the DSP. The purpose of the Guide is to enhance your life, and your role as a DSP. It is our hope that this Guide will improve the quality of life for you and the people who receive your support. Our goal is to offer insight and information, which you will find useful in your role and with the responsibilities as a DSP. We have included a list of agencies and resources for the Louisville area where you can find help when you need it, and find information to help you make decisions.

This Guide is not meant to replace supervision or any other professional advice. Instead, the information provided in this guide is to be used by you as a practical resource/reference. To be clear, in no way does this Guide override any of the policies and procedures of your employer.

Before we begin allow us to say **THANK YOU** for all you do. **YOU** really do make a difference in the lives of the people you support.



## **The National Alliance for Direct Support Professional**



The NADSP is a coalition of organizations and individuals committed to strengthening the quality of human service support by strengthening the direct support workforce. The group has representatives from the fields of mental health, developmental disabilities, child welfare, education, and many others in the human services community. The Alliance has developed a national agenda to address conditions chronicled for 25 years that are harmful to people who rely on human services. These conditions include high staff turnover, low social status, insufficient training, limited educational and career opportunities, and poor wages. These undermine the commitment of the Direct Support Professionals, and have made it very difficult to recruit and train qualified and committed individuals in direct support roles in every area of human services.

The NADSP believes that service participants and direct support professionals are partners in the move towards a self-determined life, and in complimenting and facilitating growth of natural supports. We recognize that people needing support are more likely to fulfill their life dreams if they have well-trained, experienced, and motivated people at their side in long-term, stable, compatible support relationships. We also recognize that well-planned workforce development strategies are needed to strengthen our workforce.

### **Code of Ethics of the National Alliance of Direct Support Professionals**

#### **Preamble**

Direct Support Professionals (DSPs) who support people in their communities are called upon to make independent judgments on a daily basis that involve both practical and ethical reasoning. The people who assume the support role must examine and call upon values and beliefs, as well as creative vision, to assist them in the complex work they perform.

A primary purpose of the DSP is to assist people who need support to lead self-directed lives and to participate fully in our communities and nation.

This emphasis on empowerment and participation is critical because the prejudices of society form powerful barriers that prevent many people with mental or physical disabilities from enjoying a high quality of life. And, too often, the very social policies and service systems designed to help can create other barriers.

Therefore, it must be the mission of the DSP to follow the individual path suggested by the unique gifts, preferences, and needs of each person they support, and to walk in partnership with the person, and those who love him or her, toward a life of opportunity, well-being, freedom, and contribution. Unfortunately, there have been no set criteria to guide these journeys as there are for other professional groups (such as doctors, nurses, service coordinators, and social workers) who have intimate knowledge of and responsibility for another person's emotional, financial, or physical being. There is no other position today in which ethical practice and standards are more important than direct support professionals. DSPs are often asked to





serve as gatekeepers between people needing support and almost every aspect of their lives, including access to community, personal finances, physical well being, relationships, employment, and everyday choices. The whole landscape of a person's life can change with the coming and going of these critical support people.

As a result of these work duties, DSPs face ethical decisions on a daily basis and consistently feel the tension between the ideals of the professional and its practice. There are numerous pressures coming from organizations, government, social policy, and societal prejudice that can shift focus and allegiance away from those supported. In order to maintain the promise of partnership and respect that must exist in a helping relationship, a strong ethical foundation is critical to help DSPs navigate the maze of influences that bombard them.

This issue has led to the efforts on the part of the National Alliance for Direct Support Professionals (NADSP) to identify the kinds of ethical situations that DSPs face and to develop a set of ethical guidelines. The NADSP convened a national panel of DSPs, advocates, families, professionals, and researchers who constructed this code of ethics. Focus groups and surveys regarding the draft language were conducted throughout the country and were integrated to create the final code. This Code of Ethics is intended to serve as a straightforward and relevant ethical guide, shedding light on the shared path to a self-directed life. It is intended to guide DSPs in resolving ethical dilemmas they face every day and to encourage DSPs to achieve the highest ideals of the profession.

The skills and knowledge of community support practice must be joined with the ethical principles to create the environment needed to fully support people. To do so effectively, we must all work toward recognizing DSPs as professionals who have skills, knowledge, and values that constitute a unique and important profession. There must be a commitment to hiring, developing, and supporting DSPs who have a healthy sense of their own worth and potential, and the work and potential of the people they support, and who can infuse these beliefs into practice. DSPs themselves must know that it is part of their role to foster a spirit of cooperation and mutual responsibility with other DSPs regarding ethical practice.

Direct Support Professionals, agency leaders, policymakers, and people receiving services are urged to read the Code and to consider ways that these ethical statements can be incorporated into daily practice. The beliefs and attitudes that are associated with being an effective human service professional are the cornerstones of this code. This code is not the handbook of the profession, but rather a roadmap to assist us in staying the course of securing freedom, justice and equality for all.

## **1. Person- Centered Supports**

As a DSP, my first allegiance is to the person I support; all other activities and functions I perform flow from this allegiance.







### **As a DSP, I will –**

Recognize that each person must direct his or her own life and support and that the unique social network, circumstances, personality, preferences, needs and gifts of each person I support must be the primary guide for the selection, structure, and use of supports for the individual. Commit to person- centered supports as best practice.

Provide advocacy when the needs of the system override those of the individual(s) I support, or when individual preferences, needs or gifts are neglected for other reasons.

Honor the personality, preferences, culture and gifts of people who cannot speak by seeking other ways of understanding them.

Focus first on the person, and understand that my role in direct supports will require flexibility, creativity and commitment.

## **2. Promoting Physical and Emotional Well-Being**

As a DSP, I am responsible for supporting the emotional, physical, and personal well-being of the individual receiving support. I will encourage growth and recognize the autonomy of the individuals receiving support while being attentive and energetic in reducing their risk of harm.

### **As a DSP, I will –**

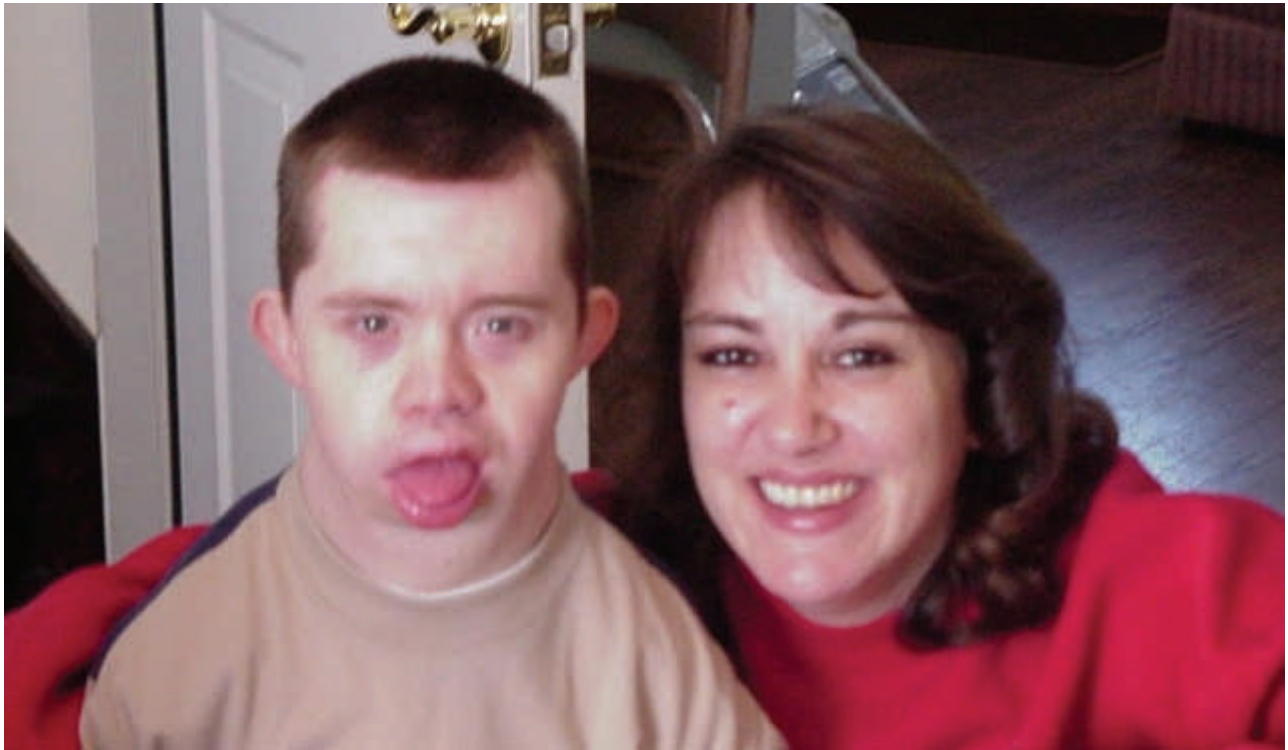
Develop a relationship with the person I support that is respectful, based on mutual trust, and that maintains professional boundaries.

Assist the individuals I support to understand their options and the possible consequences of these options as they relate to their physical health and emotional well-being.

Promote and protect the health, safety, and emotional well being of an individual by assisting the person in preventing illness and avoiding unsafe activity. I will work with the individual and his or her support network to identify areas of risk and to create safeguards specific to these concerns.

Know and respect the values of the people I support and facilitate their expression of choices related to those values.

Challenge others, including support team members (e.g. doctors, nurses, therapists, co-workers, family members) to recognize and support the rights of individuals to make informed decisions even when these decisions involve personal risk.



Be vigilant in identifying, discussing with others, and reporting any situation in which the individuals I support are at risk of abuse, neglect, exploitation or harm.

Consistently address challenging behaviors proactively, respectfully, and by avoiding the use of aversive or deprivation intervention techniques. If these techniques are included in an approved support plan I will work diligently to find alternatives and will advocate for the eventual elimination of these techniques from the person's plan.



### 3. Integrity and Responsibility

As a DSP, I will support the mission and vitality of my profession to assist people in leading self-directed lives and to foster a spirit of partnership with the people I support, other professionals, and the community.

#### **As a DSP, I will –**

Be conscious of my own values and how they influence my professional decisions.

Maintain competency in my profession through learning and ongoing communication with others.



Assume responsibility and accountability for my decisions and actions. Actively seek advice and guidance on ethical issues from others as needed when making decisions.

Recognize the importance of modeling valued behaviors to co-workers, persons receiving support, and the community - at- large.

Practice responsible work habits.

#### 4. Confidentiality

**As a DSP,** I will safeguard and respect the confidentiality and privacy of the people I support.

**As a DSP, I will –**

Seek information directly from those I support regarding their wishes in how, when and with whom privileged information should be shared.

Seek out a qualified individual who can help me clarify situations where the correct course of action is not clear.

Recognize that confidentiality agreements with individuals should be broken if there is imminent harm to others or to the person I support.



#### 5. Justice, Fairness and Equity

**As a DSP,** I will promote and practice justice, fairness, and equity for the people I support and the community as a whole. I will affirm the human rights, civil rights and responsibilities of the people I support.

**As a DSP, I will –**

Help the people I support use the opportunities and the resources of the community available to everyone.

Help the individuals I support understand and express their rights and responsibilities.

Understand the guardianship or other legal representation of individuals I support, and work in partnership with legal representatives to assure that the individual's preferences and interests are honored.



#### 6. Respect

**As a DSP,** I will respect the human dignity and uniqueness of the people I support. I will recognize each person I support as valuable and help others understand their value.

**As a DSP, I will –**

Seek to understand the individuals I support today in the context of their personal history, their social and family networks, and their hopes and dreams for the future.

Honor the choices and preferences of the people I support.

Protect the privacy of the people I support.

Uphold the human rights of the people I support.

Interact with the people I support in a respectful manner.

Recognize and respect the cultural context (e.g. religion, sexual orientation, ethnicity, social-economic class) of the person supported and his/her social network.

Provide opportunities and supports that help the individuals I support be viewed with respect and as integral members of their communities.

## 7. Relationships

**As a DSP,** I will assist the people I support to develop and maintain relationships.

**As a DSP, I will –**

Advocate for the people I support when they do not have access to opportunities and education to facilitate building and maintain relationships.

Assure that people have the opportunity to make informed choices in safely expressing their Sexuality.

Recognize the importance of relationships and proactively facilitate relationships between the people I support, their family and friends.

Separate my own personal beliefs and expectations regarding relationships (including sexual relationships) from those desired by the people I support based on their personal preferences. If I am unable to separate my own beliefs/preferences in a given situation, I will actively remove myself from the situation.

Refrain from expressing negative views, harsh judgments, and stereotyping of people close to the individuals I support.



## 8. Self-Determination

**As a DSP,** I will assist the people I support to direct the course of their own lives.

**As a DSP, I will –**

Work in partnership with others to support individuals leading self-directed lives.

Honor the individual's rights to assume risk in an informed manner.

Recognize that each individual has potential for lifelong learning and growth.

## 9. Advocacy

**As a DSP,** I will advocate with the people I support for justice, inclusion and full participation.



### **As a DSP, I will –**

Support individuals to speak for themselves in all matters where my assistance is needed.

Represent the best interests of people who cannot speak for themselves by finding alternative ways of understanding their needs, including gathering information from others who represent their best interest.

Advocate for laws, policies, and supports that promote justice and inclusion for people with disabilities and other groups who have been disempowered.

Promote human, legal, and civil rights of all people and assist others to understand these rights.

Recognize that those who victimize people with disabilities whether criminally or civilly must be held accountable for their actions.

Find additional advocacy services when those that I provide are not sufficient.

Consult with people I trust when I am unsure of the appropriate course of action in my advocacy efforts.

### **National Alliance for Direct Support Professionals Guiding Principles**

The National Alliance for Direct Support Professionals mission is to promote the development of a highly competent human services workforce which supports individuals in achieving their life goals. We have organized our membership into committees to develop strategies to address each of the following goals (in order of priority):



1. Enhance the status of direct support professionals.
2. Provide better access for all direct support professionals to high quality educational experiences (e.g., in-service training, continuing and higher education) and lifelong learning, which enhances competency.
3. Strengthen the working relationships and partnerships between direct support professionals, self-advocates, and other consumer groups and families.
4. Promote systems reform, which provides incentives for educational experiences, increased compensation, and access to career pathways for direct support professionals through the promotion of policy initiatives (e.g., legislation, funding, practices).
5. Support the development and implementation of a national volunteer credentialing process for direct support professional.

**For more information on The NADSP go to [www.nadsp.org](http://www.nadsp.org)**



## Community Support Skill Standards (CSSS)

### Overview

The Community Support Skill Standards (CSSS) were created as part of an effort to define the core skills at the heart of community support work. The CSSS were developed by pulling together Direct Support Professionals (DSP) from a variety of human service settings, consumers of services, trainers, agency administrators, educators, and others who are invested in quality services, and working with them to identify and define the skills that DSPs need in order to support people with disabilities in leading self-directed lives, contributing to their communities and encouraging the attitudes and behaviors that enhance inclusion in the community. The CSSS are not a set of minimal criteria that a person needs to start in direct support. Instead, the standards reflect the skills, knowledge and attitudes of an experienced worker who is recognized by peers and supervisors as skilled and competent.



### Competency Areas

The CSSS competency statements and the related skill standards are listed below. There are 12 Competency areas ranging from Participant Empowerment to Documentation. Under each broad competency statement there are several skill standard statements, which describe job function in the competency.

**Competency Area 1: Participant Empowerment** The competent community support human service practitioner (CSHSP) or DSP enhances the ability of the participant to lead a self-determining life by providing the support and information necessary to build self-esteem, and assertiveness; and to make decisions. The competent DSP

#### Skill Standards:

- assists and supports the participant to develop strategies, make informed choices, follow through on responsibilities, and take risks.

- promotes participant partnership in the design of support services, consulting the person and involving him or her in the support process.

- provides opportunities for the participant to be a self-advocate by increasing awareness of self-advocacy methods and techniques, encouraging and assisting the participant to speak on his or her own behalf, and providing information on peer support and self-advocacy groups.

- provides information about human, legal, civil rights and other resources, facilitates access to such information and assists the participant to use information for self-advocacy and decision-making about living, work and social relationships.

**Competency Area 2: Communication** The community support human service practitioner or

DSP should be knowledgeable about the range of effective communication strategies and skills necessary to establish a collaborative relationship with the participant.



**Skill Standards:** The Competent CSHSP and DSP:

- uses effective, sensitive communication skills to build rapport and channels of communication by recognizing and adapting to the range of participant communication styles.

- has knowledge of and uses modes of communication that are appropriate to the communication needs of participants.

- learns and uses terminology appropriately, explaining as necessary to ensure participant understanding.

**Competency Area 3: Assessment** The community support human service practitioner and DSP should be knowledgeable about formal and informal assessment practices in order to respond to the needs, desires, and interests of the participants.

**Skill Standard:** The competent CSHSP and DSP:

- initiates or assists in the initiation of an assessment process by gathering information (e.g., participant's self-assessment history, prior records, test results, additional evaluation) and informing the participant about what to expect throughout the assessment process.

- conducts or arranges for assessments to determine the needs, preferences, and capabilities of the participants using appropriate assessment tools and strategies, reviewing the process for inconsistencies, and making corrections as necessary.

- discusses findings and recommendations with the participant in a clear and understandable manner, following up on results and reevaluating the findings as necessary.

**Competency Area 4: Community and Service Networking** The community support human service practitioner should be knowledgeable about the formal and informal supports available in his or her community and skilled in assisting the participant to identify and gain access to such supports.

**Skill Standard:** The Competent CSHSP and DSP:

- helps to identify the needs of the participant for community supports, working with the participant's informal support systems, and assisting with, or initiating the identification of community connections.

- researches, develops, and maintains information on community and other resources relevant to the needs of participants.

- ensures participant access to needed community resources coordinating supports across agencies.

-participates in outreach to potential participants.

**Competency Area 5: Facilitation of Services** The community support human service practitioner is knowledgeable about the range of participatory planning techniques and is skilled in implementing plans in a collaborative and expeditious manner.

**Skill Standards:** The Competent CSHSP and DSP

-maintains collaborative professional relationships with the participant and all support team members (including family/friends), follows ethical standards of practice (e.g., confidentiality, informed consent, etc.) and recognizes his or her own personal limitations.

-assists and/or facilitates the development of an individualized plan based on participants preferences, needs, and interests.

-assists and/or facilitates the implementation of an individualized plan to achieve specific outcomes and derived from participants preferences, needs and interests.

-assists and/or facilitates the review of the achievement of individual participant outcomes.

**Competency Area 6: Community Living Skills & Supports** The community support human service practitioner has the ability to match specific supports and interventions to the unique needs of individual participants and recognizes the importance of friends, family and community relationships.

**Skill Standards:** The Competent CSHSP & DSP

-assists the participant to meet his or her physical (e.g., health, grooming, toileting, eating) and personal management needs (e.g., human development, human sexuality), by teaching skills, providing supports, and building on individual strengths and capabilities.

-assists the participant with household management (e.g., meal prep, laundry, cleaning, decorating) and with transportation needs to maximize his or her skills, abilities and independence.



-assists with identifying, securing and using needed equipment (e.g., adaptive equipment) and therapies (e.g., physical, occupational and communication).

-supports the participant in the development of friendships and other relationships.

-assists the participant to recruit and train service providers as needed.

**Competency Area 7: Education, Training & Self-Development** The community support human services practitioner should be able to identify areas for self-improvement, pursue necessary educational, training resources, and share knowledge with others.

**Skills Standards:** The Competent CSHSP and DSP:

- completes required training education/certification, continues professional development, and keeps abreast of relevant resources and information.

- educates participants, co-workers and community members about issues by providing information and support and facilitating training.

**Competency Area 8: Advocacy** The community support human service practitioner should be knowledgeable about the diverse challenges facing participants (e.g. human rights, legal, administrative and financial) and should be able to identify and use effective advocacy strategies to overcome such challenges.

**Skill Standards:** The competent CSHSP and DSP:

- in concert with the participant identify advocacy issues by gathering information, reviewing and analyzing all aspects of the problem.

- has current knowledge of laws, services, and community resources to assist and educate participants to secure needed supports.

- facilitates, assists, and/or represents the participant when there are barriers to his or her service needs and lobbies decision makers when appropriate to overcome barriers to services.

- interacts with and educates community members and organizations (e.g., employer, landlord, civic organization) when relevant to participant's needs or services.



**Competency Area 9: Vocational, Educational & Career Support** The community based support worker should be knowledgeable about the career and education related concerns of the participant and should be able to mobilize the resources and support necessary to assist the participant to reach his or her goals.

**Skill Standards:** The competent CSHSP and DSP:

- explores with the participant his/her vocational interests and aptitudes, assists in preparing for job or school entry, and reviews opportunities for continued career growth.

- assists the participant in identifying job/training opportunities and marketing his/her capabilities and services.

- collaborates with employers and school personnel to support the participant, adapting the



environment, and providing job retention supports.

**Competency Area 10: Crisis Intervention** The community support human service practitioner should be knowledgeable about crisis prevention, intervention and resolution techniques and should match such techniques to particular circumstances and individuals.

**Skill Standards:** The competent CSHSP and DSP:

- identifies the crisis, defuses the situation, evaluates and determines an intervention strategy and contacts necessary supports.

- continues to monitor crisis situations, discussing the incident with authorized staff and participant(s), adjusting supports and the environment, and complying with regulations for reporting.

**Competency Area 11: Organization Participation** The community based support worker is familiar with the mission and practices of the support organization and participates in the life of the organization.

**Skill Standards:** The competent CSHSP and DSP:

- contributes to program evaluations, and helps to set organizational priorities to ensure quality.

- incorporates sensitivity to cultural religious, racial, disability, and gender issues into daily practices and interactions.

- provides and accepts co-workers support, participating in supportive supervision, performance evaluation, and contribution to the screening of potential employees.

- provides input into budget priorities, identifying ways to provide services in a more cost-beneficial manner.

**Competency Area 12: Documentation** The community based support worker is aware of the requirements for documentation in his or her organization and is able to manage these requirements efficiently.

**Skill Standards:** The competent CSHSP and DSP

- maintains accurate records, collecting, compiling and evaluating data, and submitting records to appropriate sources in a timely fashion.

- maintains standards of confidentiality and ethical practice.

- learns and remains current with appropriate documentation systems, setting priorities and developing a system to manage documentation.

## Understanding Kentucky's Service System

Welcome to the mental retardation/developmental disabilities service system in Kentucky. It may interest you to know how the system works and where funding comes from that pays for the services received by those you support. Although the following information does not include all funding sources and resources, it will give you an overview of the primary sources of funding for the MR/DD services system.



### The Division of Mental Retardation

The Division of Mental Retardation (DMR) is the lead agency for services and supports for people with mental retardation/developmental disabilities in Kentucky, and it is part of The Department of Mental Health and Mental Retardation Services within the Cabinet for Health and Family Services. At this time, Patrick Wear is the Commissioner of the Department of Mental Health/Mental Retardation, and was appointed by the Mark Birdwhistell, the Secretary of the Cabinet for Health and Family Services, and the Governor approved his appointment. Betsy Dunigan is the acting director of the Division of Mental Retardation. The DMR office is located in Frankfort (100 Fair Oaks, Frankfort, KY 40601) and the phone number is 502-564-7700.

The Division of Mental Retardation (DMR) provides oversight and funding for both institutional care (Intermediate Care Facilities for Persons with Mental Retardation) and community-based services. In our community there are two public ICF-MR facilities- Hazelwood and Central State) and one private ICF- MR Cedar Lake Lodge.

The majority of persons within the state are served in community-based programs within the regional comprehensive care system. In our area (Jefferson, Bullitt, Spencer, Oldham, Henry, Shelby and Trimble), Seven Counties Services in the regional service provider and planner. Seven Counties also collaborates with a network of service providers through affiliation agreements to provide community-based services to people with mental retardation/developmental disabilities.

While the DMR provides broad guidelines for services throughout the state, monitoring of services and funding of the community-based system is operated on a regional or local level. DMR provides important funding incentives for non-Medicaid and programs throughout the state.

For many years the Department of Medicaid Services has funded institutional programs within the state. In recent years Medicaid funding has become a major source of revenue for community-based programs. At this time, DMR is under contract with the Department of Medicaid Services to administer the Supports for Community Living (SCL) waiver program. (See below for more information). The DMR also administers the Pre-admission Screening and Resident Review (PASRR), Social Services and Equipment Fund, and the Supported living Program in Kentucky.

A large contributing resource to the continuation and implementation of the developmental services program is what is referred to as the Medicaid waiver program, which comes from The Centers for Medicare and Medicaid Services (CMS) a Federal agency within the U.S. Department of Health and Human Services. Kentucky has three (3) waivers that you will come into contact with. They are: The Supports for Community Living (SCL) Home and Community Based Services (HCBS) and the Acquired Brain Injury (ABI). Essentially the waiver means that care in certain facilities (nursing facility or Intermediate Care Facility for the Mentally Retarded) is being waived in favor of Home and Community Based Care. By participating in the Waiver program, Kentucky is able to increase its resources available to people with mental retardation and developmental disabilities that are found eligible under the waiver. For every dollar the State appropriates to services provided under the waiver, the federal government matches it with another dollar. Without this federal investment in community-based services, the system would be drastically under-funded and many people would be unable to reside in their communities. *For more specific information regarding the above waivers contact your employer.*

The adult developmental services system is not an entitlement program. Simply being eligible for services does not guarantee that one will receive the services they need. Services are provided to the extent that resources have been made available through the combined Congressional and Legislative budgeting and appropriation process and the state and MH/MR Boards contracting processes. In Kentucky, once the Legislature and Governor complete the budget and appropriation processes, state agencies receive their biennial allocations through their respective departments. In this case, DMR receives verification of funding from the Cabinet of Health and Family Services. This allows DMR to contract with the MH/MR Boards. The MH/ MR Boards work in similar fashion with the agencies they contract with.

#### The Department of Medicaid Services

Medicaid is the largest single funder of community-based services in Kentucky and within our region. The Centers for Medicare and Medicaid Services (CMS), a Federal agency within the U.S. Department of Health and Human Services, provides funds for Kentucky's three (3) waiver programs that serve many of people with whom you work: Supports for Community Living (SCL), Home and Community Based Services (HCBS), and the Acquired Brain Injury (ABI). Essentially, a "waiver" means that care in certain facilities (nursing facility or ICF- MR/DD) for persons with disabilities is being waived in favor of care in a community-based setting.

Medicaid funding is appealing to states because it is a match program- for every \$1 provided by the state of Kentucky, the federal government provides \$3. Thus, Kentucky is able to increase the resources available to people with MR/DD. Without this federal investment in community-based services, the whole system of care would be drastically under-funded and many people would be without services. The use of Medicaid funding often increases the amount of oversight, record keeping, and medical- orientation of services. It is also important to remember that Medicaid Services are based on individual eligibility, and agencies receive funding based only on the clients they serve that are eligible for Medicaid reimbursement. *For more specific information regarding the above waivers contact your employer.*

## Other Funding Resources

While every community and region within the state is very different, it should be noted that in our region there are a number of other funding sources for children and adults with disabilities. Many agencies are actively involved in fund raising (special events, annual campaigns, fees for service) activities that assist in underwriting the cost of their programs. This is especially true of agencies providing services to persons who are not part of the above-mentioned waiver programs. Other funding sources include, but are not limited to, Metro United Way, Louisville Metro Government, WHAS Crusade for Children, foundation grants, etc.



## Entitlement Programs

Within the broad service system for persons with disabilities, there are some services that are considered “entitlement services” or services that the local community or region or state is required by law to provide. The best examples of entitlement programs are public school programs- special education programs for all children from 3-21 who are disabled- and the First Steps program, a mandated program for all infants and toddlers who have disabilities or are at risk of having disabilities.

It is important to remember that adult services for persons with MR/DD are NOT entitlement programs. Simply being eligible for services does not guarantee that needed services will be received. Instead, services are provided to the extent that resources are made available through the federal, state, regional, and local funders. In Kentucky, the Governor and ultimately the General Assembly complete the budget and appropriation processes, and state agencies receive their biennial allocations. DMR, for example, receives verification of funding from the Cabinet of Health and Family Services. This allows DMR to contract with the MH/MR Comprehensive Care Center for service provision. The budget process also limits the Medicaid funding, as the state must provide the state match for any and all Medicaid reimbursement.

Private funding and local program support often reflects the general economy of the community and is not considered “entitlement.”



## **Don't Forget About the Families...**

### **Bridging the Gap Effective Communication with Families**

By Terri Niland, Co-Resident Counselor, Montgomery County, Maryland

Perhaps one of the greatest challenges facing the Direct Support professional (DSP) lies in effectively communicating with families. As a resident counselor of more than five years in an Alternative Living Unit, I have worked closely with the families of the three women who live there. In addition to maintaining regular contact with those families who are fully involved, I have encouraged additional contact with family members whose involvement has been minimal. In order to nurture these contacts, I believe one of the most important things to keep in mind is that the ultimate goal of any such communication is to serve the best interest of the individual to whom I provide supports. I have found the following strategies to be helpful for maintaining this best interest while fostering positive interactions with families.



**Take the initiative** – All too frequently, it is a family member who initiates contact with the DSP. The DSP, however, needs to initiate communication. For example, I see the frustration of families who are not notified about staff changes. Initiating communication shows your interest in the individual as well as shows the value you place on those who are closest to the individuals you serve.

**Communication early in the relationship** – Early communication is essential to getting the relationship off to a good start. There is nothing more frustrating than when the initial point of contact between a DSP and family member involves a problem. Overcoming a negative beginning can be difficult. Communicating early on positive grounds goes a long way in getting the relationship off to a good start.

**Work as a team** – The relationship between families and DSPs should not be adversarial. Rather, their relationship should be characterized by a willingness to work together to serve the best interests of the individual.

**Share information with other staff members** – Staff members sharing among themselves enhances communication with families. By sharing information provided by families, as well as serving as a sounding board for one another, the DSP can improve the quality of care they provide. Furthermore, helping each other learn how to work effectively with family members can be a vital part of this communication.

Use a variety of methods – Speaking with family members and writing them notes are just two methods of communication. Be creative! Be practical! One of the most effective means of communication I have with families involves making detailed notations in bankbooks. When a withdrawal is made, I write a description of how the money will be spent. The families are very appreciative of this record.

Be honest – Honesty in your interaction with families is an essential ingredient to effective communication. Learn how to best approach family members with what needs to be said. What works well with one family might not work with another.

Be an advocate. As DSPs, we have a dual role. Not only are we responsible for the day-to-day care of the individuals we serve, we are also called to advocate on their behalf. This is probably one of our most important functions, as it involves serving the best interest of those with whom we work. At times, being an advocate will involve working together with family members on behalf of the individual. At other times, it might involve advocating on behalf of the individual in matters with which the family might disagree.

Show you care – Your genuine concern for the individual, as well as for their family members, will serve you well. Sharing observations with family members as well as asking for their input will go along way in maintaining positive communication. In addition, attending to detail and knowing what values are important to family members will be helpful as well. Your genuine care and concern will earn you respect that will foster your positive relationships with families.

These are a few ways I have found that have improved both the lives of the people I provide supports to and my work. As DSPs, we can greatly improve the quality of our services simply by looking for more effective and creative way to communicate, especially with families.



## The Power of One: A letter to the Direct Support Professional

By Jan Barthle, a parent of a adult women with a multiple disabilities

***“To us it is really simple – if agencies have good staff, we have good lives. If agencies have bad staff who aren’t trained, don’t understand our disabilities or have attitude problems, we suffer the effects.”***

Dear Friend:

The quote above applies to the lives of the parents of a loved one with a disability almost as much as it obviously applies to the people with disabilities in your care, a direct support professional. We worry a lot about the physical health and safety of our children, but even more

than that we worry about how they are being treated. Your influence will be substantial in their emotional and psychological health as well. You might quickly become one of the most important persons in their lives. Whether you know it or not, you will become so essential to them that they may become sick or emotionally unbalanced should you have to leave your position of care. Because many persons with disabilities are so dependent on others not only for their care but also for their survival, they are very vulnerable. Your role as a Direct Support Professional (DSP) is so powerful that you can make or break their lives and their spirit. **It is both a wonderful and a daunting responsibility.**

The way you respond to persons in your care and how you treat them will help them to either believe in themselves or to despair of ever being worthwhile. They will read your face and your body language long before you ever utter a word. Like many who have faced discrimination and oppression all their lives, they have learned to read people and know in a heartbeat how they are regarded. The way you interact with them will tell them who they are. The respect or lack of respect with which they are addressed and the way you interact with them will determine how they feel about themselves. **You will be their mirror. Reflect on them well!**

Your multiple roles as a DSP should qualify you for an Academy Award since you will constantly juggle the roles of a parent, teacher, friend, counselor, nurse, chauffeur, financial manager, social coordinator, relationship consultant, and sometimes even a spiritual advisor. **Direct support is the most challenging job you will ever have and one of the most rewarding.**

**Remember this about the people you will support, someone may not talk but will surely communicate; she may not walk but she loves to dance; he may not understand everything you say to him but he understands love. You may be the one who sees some gift in our adult child that no one has seen before. You will learn to look inside; you will tap potential no one knew was there. It is widely recognized that people who need support are more likely to fulfill their life dreams if they have well trained, experienced, and motivated professionals at their sides in long-term, stable, compatible support relationships.** There are many kinds of support. Of course, if you do personal care, the physical work you do is essential (and please do it with dignity and respect). But beyond that is the role you play in helping people learn and grow, giving wings to their hopes and dreams while at the same time being their safe landing, their rock of security in a life filled with change and insecurity. Support them well!

Now let's take some time to better understand us: their parents, caregivers, and families. We have also become who we are by the way we and our children have been treated, we have been shaped by our experiences, for better or for worse. Our lives, in many ways, reflect the journey we have been on. The road has not been easy. We have had to literally fight for the rights of our children at every turn- to be in a regular day care, to attend public schools, to play baseball, to be in Sunday School with the rest of the kids, to join Girl Scouts or become a Boy Scout, to go to camp, to attend a school dance, to be in the ring ceremony, to have a life, to have a job. We have had to wrestle for every opportunity that others are freely given. So we have a hard time believing that anyone else will be there for them. We have a hard time letting go. We want to rely on you to be there for our children, we want to believe in you. **Now we trust them to you, we hope you will live up to that trust!**

These people you see before you were (and in some ways) will always be our babies. Sure we're overprotective but believe this, we had good reasons. We have seen our children treated in ways that would make your blood boil. So even though our child is now an adult, we feel we need to continue our parental role until someone can take our place in his or her lives. As typical children grow up into adulthood, they naturally separate from their parents and form their own identities. That process of individuation is much more difficult for a young adult with a disability. Many of our children have never taken part in the ordinary milestones that mark a child's life and progression into maturity – like being invited to a birthday party or sleepover, making First Holy Communion, being invited to the Prom. He or she may be more dependent both physically and emotionally on parents than usual. Thus "childhood" is prolonged in ways that may be damaging to the self-image and the need for independence that a young adult typically experiences.

Now we release them to you, we are partners in this endeavor. **We shaped their past. You will now shape their future.** We know what they needed as children, you will teach them what they need as adults. You are their model for how an adult manages one's life. From you they learn how to act as an adult in relationship to other, how to support others, how to take responsibility. Through you they will learn how people keep their promises. They will see in your eyes what possibilities there are for them to have an identity separate from their families. **You are now a mentor and a model. It is our hope that you will do it well!**

**We know we need to let go, but we can only let go into capable hands and to a loving heart. We ask you to be those capable hands. We ask you to carry them in your hearts. You will take them to a place beyond us and teach them to live their own lives when we are someday out of their reach. You are the captain of the space ship that carries our children across time to adulthood. Lead well, live long and prosper!**



## What's This Thing Called Self-Advocacy and Self-Determination

### Self-Advocacy

There are many Self-Advocacy groups nationally in which people who have developmental disabilities are claiming their citizenship and becoming empowered to speak up for themselves. For Self-Advocates who are involved in these formal groups, DSP's play an integral role in providing transportation, encouraging active participation and promoting learning opportunities for personal growth.

For individuals with developmental disabilities who do not wish to belong to formal Self-Advocacy groups, the role of the DSP is unique in fostering the skills of self-advocacy to achieve full community inclusion, civic participation, and the rights and responsibilities of citizenship.

If you are interested in obtaining information on our area's Self-Advocacy groups contact The Self-Advocacy Connection of Metro Louisville at 502-587-6500 or Louisville Self-Advocates in Action at 502-454-9664.



### Self-Determination

As a DSP who supports people with disabilities, you may be hearing more about promoting self-determination, but you may not know exactly what it is or what it ought to look like in the lives of individuals. Self-determination is not the same as choice making, independence, or self-advocacy, but is made up of many different things. There are probably as many ways to think about it as there are people in the world. It refers to making plans and having ultimate control over both larger life decisions such as selecting a new place to live, or quitting a job, as well as everyday choices such as what shirt to wear, or who to receive help from when needed.

It is assumed for most people in our society that they have the ultimate right to control their own lives and therefore they are encouraged to do so at an early age. However, in our desire to protect people with disabilities we have not offered them the same opportunities to live a life of their own choosing. A role for today's DSP is to give control over large and small life decisions back to persons with disabilities, but also to continue providing support based on helping each person achieve the lifestyle of his or her choosing. Finding this balance is part of the "art" of the DSP's job. **Excerpts taken from the Quarterly Newsletter of the National Alliance for Direct Support Professionals -Frontline Initiative.**

### Supporting Self-Determination

#### Through Self-Reflection by Heidi Maas

As someone who has many medical needs, but many dreams as well, I'd like to share with you what self-determination means to me, and how my situation demonstrates what a DSP can do to promote the self-determination of the people they support. For me, self-

determination is expressed primarily in two ways: 1) speaking up for myself, and 2) learning more about my medical needs and how to cope with them on a daily basis. First let me share a little background about myself.

I have Prader-Willi Syndrome, diabetes and a developmental disability. Prader-Willi Syndrome is an eating disorder that was described to me as my brain telling me to eat constantly but never telling me that I feel full. Every day I feel the struggles of having to watch what I eat and exercising every day. I have to use will power to help me control my urges. I feel better when I stick to my diet, and when my staff helps me with these ongoing struggles by encouraging me to stick with it. Having diabetes, I also have to check my blood sugar four times a day and, again, I watch my diet carefully. My staff provides supports throughout all of this, but sometimes their eagerness to stick with the program has resulted not only in a clash of wills, but even a risk to my health.



For instance, one time I told staff that I didn't have enough to eat for breakfast, but she didn't listen. She told me she couldn't do anything about it and that I needed to stick with my diet. I left for work. I started feeling light headed and weak, my legs like jelly. I had to go to the staff at work to get something to raise my blood-sugar level. When I got home I was able to tell the supervisor what happened and she said she would take care of it. It has never happened again. Staff now support me by listening to me more carefully and responding to my needs. When that happens, I feel respected, self-confident and self-reliant. My situation is delicately balanced between what I want and what I need. DSP's need to be very sensitive to everything I say, whether it be something I want to do for fun, or how much I want for breakfast, and they need to work with me to find a solution.

I feel that, to be most effective, DSPs must not only be aware of my needs and wants but also their own. In the above situation about breakfast, the staff seemed callous, rigid and almost oblivious to me. In this case and in many like it, the DSP's self-understanding may have affected how she understood and sympathized with others. Many people are rigid with others in areas where they themselves do not feel they are doing their best. Perhaps if she understood her own needs, she may have understood mine better and responded more appropriately.

I recently participated on a consumer empowerment panel where these types of issues were addressed. The panel shared a set of questions with DSPs which may help them during times when they struggle with consideration of a person's self-determination. These were the questions a DSP might want to ask him or herself:

-Are you struggling as a staff person to understand someone's choices? If so, ask yourself why you are having difficulty accepting that she is making the choices she is according to her life experience and values, not according to yours.

-Do you find yourself feeling angry and frustrated with the person with a disability? Try to identify what it is about the individual's behavior that threatens you. (Remember that anger can interfere with your role as a support person).

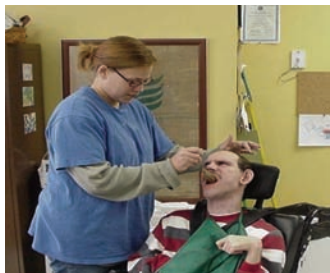
-With which person do you find it difficult to be compassionate? Why?

It is the challenge of the DSP to question and examine him or herself and ask how this self-understanding can affect the way they support me as well as affect my self-determination. As a person with various disabilities, I understand how a DSP may want to “protect” me. But I want to be in charge of my life.

## **Building Supportive Relationships**

The Key to Quality Direct Service

by Lori Schluttenhofer, Residential Supervisor, Minneapolis Minnesota



Take some time to imagine a life in which the central figures in your daily life are there for the sole purpose of collecting a paycheck. People only talk to you about what you should or shouldn't do. They decide when you wake, eat, bath, and sleep. And it's been a long time since anyone had an actual conversation that included your input—usually these conversations go on without you or as though you were invisible.

This is the life that many people with disabilities experience. Is it any surprise then that many of the people who receive supports lack the skills and knowledge necessary for interpersonal relationships? Is it any surprise that low self-esteem is so pervasive among consumers of support services?

Positive, growth-supportive relationships between direct support staff and the people who receive services are a necessity which has long been overlooked. In fact, it has repeatedly been stressed that we need to adhere to stringent “staff-client” boundaries, in which our roles as service providers are strictly maintained in an emotional vacuum. We've been taught to always remember that we're “staff,” never friends. This perspective is now being replaced by a growing understanding of the multi-faceted nature of our roles and of the importance of relationships. We're not only counselors, teachers, supervisors, or caregivers, but also learners, mentors, friends, and real people—real people who communicate, respect others, support joint growth, and commit themselves to these principles. Only building and maintaining meaningful relationships with the people we support can we foster real, lasting growth for them as well as for ourselves.

Mutual respect and understanding are the building blocks for supportive relationships. This involves a resolution that all people, regardless of ability, are entitled to the same levels of self-expression, self-determination, and positive regard. This seems very simple in theory, but often becomes lost in practice. For instance, some direct support professionals develop a “split- personality” — a distinct difference in voice tone, manner, and facial expression used when communicating with people with disabilities. The same lack of respect is communicated when staff talks about someone's life without regard for their presence or input.

In order to relate to each other, and to communicate, we must first listen. We often spend so much of our “work” time talking and very little actually listening to the people we support. We get so lost in striving toward goals set by assessments and legal regulations that we don't take enough time to try to hear and observe what people are really expressing. We need to

take time to really get to know each person as a person rather than a case history or a diagnosis. When it comes time to talk, it's important to avoid esteem-defeating, labeling language, and rely on accurate, descriptive language.

Perhaps the most important factor, though, is to simply be a real person and expect the same of others. A real person experiences a variety of emotions and possesses a variety of expectations regarding others, and a real person shares some of these with those to whom he chooses to relate.

Building a solid relationship requires a steadfast commitment to consistency of positive re-



gard. In order to have a healthy sense of self-esteem, everyone must spend time with others who think of them positively, regardless of accomplishment or failure. We've all worked before with people whose "bad reputations" precede them and influence how others approach or interact with them. Balanced with communicating genuine feelings and reactions, at some point we need to be able to forgive people for past mistakes and allow for a new beginning. Few of us have the misfortune of being forever labeled with a permanent record of our past trans-

gressions, and no one should be held to this standard because he or she receives supports.

So, we need to balance many roles as we offer support to people with developmental disabilities. We serve as a mix of teacher and friend and rely on the relationships we build as a foundation for mutual growth and support. By listening and learning, by speaking well and with respect, and by being genuine, we can open doors to individual growth and accomplishment, and we can truly find a better reason to do what we do- because we grow from these relationships as well.

(Re-printed from the Frontline Initiative, Volume 1 – Number 2 – winter 1997)



# A Credo for Support

by Norman Kunc and Emma Van der Klift  
Copyright 1996.

<b>Do Not</b> see my disability as the problem.	<b>Recognize</b> that my disability is an attribute.
<b>Do Not</b> see my disability as a deficit.	It is you who see me as <b>deviant</b> and <b>helpless</b> .
<b>Do Not</b> try to fix me because I am not broken.	<b>Support me</b> . I can make my contribution to the community in my own way.
<b>Do Not</b> see me as your client. I am your fellow citizen.	<b>See me as your neighbor</b> . Remember, none of us can be self-sufficient.
<b>Do Not</b> try to modify my behavior.	<b>Be still and listen</b> . What you define as inappropriate may be my attempt to communicate with you in the only way I can.
<b>Do Not</b> try to change me, you have no right.	<b>Help me learn</b> what I want to know..
<b>Do Not</b> hide your uncertainty behind professional distance.	<b>Be a person who listens</b> and does not take my struggle away from me by trying to make it all better.
<b>Do Not</b> use theories and strategies on me.	<b>Be with me</b> . And when we struggle with one another, let that give rise to self-reflection.
<b>Do Not</b> try to control me. I have the right to my power as a person.	What you call non-compliance or manipulation may actually be the only way I can <b>exert some control over my life</b> .
<b>Do Not</b> teach me to be obedient, submissive, and polite.	I need to feel entitled to <b>No</b> if I am to protect myself.
<b>Do Not</b> be charitable towards me. The last thing this world needs is another Jerry Lewis.	<b>Be my ally</b> against those who would exploit me for their own gratification.
<b>Do Not</b> try to be my friend. I deserve more than that.	<b>Get to know me</b> . We may <b>become friends</b> .
<b>Do Not</b> help me, even if it does make you feel good.	<b>Ask me if I need your help</b> . Let me show you how you can best assist me.
<b>Do Not</b> admire me. A desire to lead a full life does not warrant adoration.	<b>Respect me</b> , for respect presumes equity.
<b>Do Not</b> tell, correct, and lead.	<b>Listen, support, and follow</b> .
<b>Do Not</b> work on me.	<b>Work with me</b> .



## TAKING CARE OF YOU!

If you don't take care of yourself who will?

You have one of the most demanding jobs and you have to be up to the task! So what better way to do it then to live a healthy life?

### Things you can do to stay healthy!

1. Get a good night's sleep! Most of us are walking around, working and driving...sleep deprived! Get at least 6-8 hours nightly as your body seems to require.

2. Don't smoke, and avoid secondhand smoke.

3. Brush and floss your teeth. Good oral hygiene protects overall health, not just your teeth.



4. Eat a balanced diet that includes 5 servings of fruits and vegetables and don't skip the protein! Always eat breakfast and remember Danish on the run doesn't count!

5. Maintain a healthy weight.

6. Drink 8 to 10 glass of water per day. This is good for so many bodily functions and may reduce your risk of colon cancer and can keep your weight down as well!

7. Think about what vitamins and supplements you should be taking and take them. Most women ages 20-40 can benefit from a daily multi-calcium supplementation as well! And men don't forget the lycopene- it is great for the heart and the prostate.





8. Exercise regularly; finding a balance of strengthening, stretching and aerobic activities that will help you generate good tone, flexibility and endurance.

9. Learn to relax and let go of stressful thoughts and frustrating emotions.

10. If you haven't had your annual physical yet, take the time today to schedule it!

11. Also, do self-exams of your breasts or testes, as well as skin.

12. Work at communicating both your thoughts and your feelings clearly with your friends, co-workers and loved ones.

13. If you are taking prescription medicines, including birth controls pills, be sure to take them **AS DIRECTED**.

14. Really try not to say things out of anger when you have differences with another; remember your words can hurt as much as your actions.

15. Keep your attitude positive and try to see the best in your work and your life. If things are not going well, work at improving them.

16. Keep alcohol consumption moderate: no more than one drink daily for a woman, two drinks for a man. If you are a heavy drinker, seek counseling, and cut back or quit.

17. Fasten seat belts. Drive sober and defensively.

**And finally...**

18. **Love Yourself** and let love in your life; learn to express the wonderful way you feel about everyone around you!

19. Nourish your soul!



## A Dozen Ways to Improve Your Walking Workouts (BerkeleyWellness.com)

Of all the ways to stay fit, walking is the easiest, safest, and cheapest. It can also be the most fun: a fine day, a good companion, an attainable goal (say, a scenic spot) three or four miles away. On city streets, in the woods, or even round and round the high school track, walking is the best way to experience a landscape. If it's too rainy for anything but a treadmill indoors, at least you can read or watch TV. And after your workout, you know you've done yourself some good.

Briskly walking one mile (brisk usually means 3.5 to 4 miles per hour) burns nearly as many calories as running a mile at a moderate pace, and confers similar fitness and health benefits. Even strolling or slow walking (about 2 miles per hour) confers some benefits. This was seen in a new Harvard study of almost 40,000 female health professionals, which found that walking as little as an hour a week, at any pace, reduces the risk of coronary artery disease. Longer and more vigorous walking produced a greater risk reduction.

Here's how to get more out of your walking workouts and to vary your routine:

- **Try to walk briskly for at least half an hour every day, or one hour four times a week.** If you weigh 150 pounds, walking at 3.5 miles an hour on flat terrain burns about 300 calories per hour. So this schedule would burn about 1,100 calories a week (studies show that burning 1,000 to 2,000 calories a week in exercise helps protect against heart disease). If you can't work that into your schedule, try more frequent, shorter walks.
- **Make an effort to walk as much as possible.** Skip elevators and escalators and take the stairs. Leave the car at home if you can walk the mile or two to a friend's house. Walk to work, at least part of the way.
- **Another approach:** get a pedometer and see how many steps you take a day. Aim for 3,000, and then try to work up to at least 5,000 steps (about 2.5 miles for the average stride) in the course of your daily activities. Some Japanese health officials advise 10,000 steps as a goal, though there is no magic number. To achieve the higher goals, you'll have to include some brisk exercise walking in addition to walking at home and at work.
- **If you want to go faster,** instead of taking longer steps, take faster steps. Lengthening your stride can increase strain on your feet and legs.
- **Swing your arms.** One good option: bend them at 90° and pump from the shoulder, like race walkers do. Swing them naturally, as if you're reaching for your wallet in your back pocket. On the swing forward, your wrist should be near the center of your chest. Move your arms in opposition to your legs—swing your right arm forward as you step forward with your left leg. Keep your wrists straight, your hands unclenched, and elbows close to your sides. The vigorous arm pumping allows for a quicker pace, and provides a good workout for your upper body. And you'll burn 5 to 10% more calories.
- **Add some interval training.** For example, speed up for a minute or two every five minutes. Or alternate one fast mile with two slower miles.



• **Choose varied terrains.** Walking on grass or gravel burns more calories than walking on a track. And walking on soft sand increases caloric expenditure by almost 50%, if you can keep up the pace.

• **Walk up and down hills** to build strength and stamina and burn more calories. Combine hill walking with your regular flat-terrain walking as a form of interval training. When walking uphill, lean forward slightly, it's easier on your leg muscles. Walking downhill can be harder on your body, especially the knees, than walking uphill, and may cause muscle soreness, so slow your pace, keep your knees slightly bent, and take shorter steps.



• **Try a walking stick or poles.** A walking stick is helpful for balance, especially for older people. To enhance your upper-body workout, use lightweight, rubber-tipped trekking poles, sold in many sporting-goods stores. This is like cross-country skiing without the skis. When you step forward with the left foot, the right arm with the pole comes forward and is planted on the ground, about even with the heel of the left foot. This works the muscles of your chest and arms as well as some abdominals, while reducing the stress on your knees. Find the right size poles by testing them in the store: you should be able to grip the pole and keep your forearm about level as you walk. Many poles are now adjustable.

• **Use hand weights, but carefully.** Hand weights can boost your caloric expenditure, but they may alter your arm swing and thus lead to muscle soreness or even injury. They're generally not recommended for people with high blood pressure or heart disease. If you want to use them, start with one-pound weights and increase the weight gradually. The weights shouldn't add up to more than 10% of your body weight. Ankle weights are not recommended, as they increase the chance of injury.

• **Try backward walking for a change of pace.** It is demanding, since it's a novel activity for most people. Even a slow pace (2 mph) provides fairly intense training. "Retro" walking is also a good option if you're trying to vary your workout on a treadmill or stair-climbing machine. And if you're recovering from a knee injury, it may help. Be careful when going back-wards outdoors: choose a smooth surface and keep far away from traffic, trees, potholes, and other exercisers. A deserted track is ideal. If possible, work out with a spotter, a forward-walking partner who can keep you from bumping into something and help pace you. To avoid muscle soreness, start slowly: don't try to walk backward more than a quarter mile the first week. Elderly exercisers or anyone else with balance problems should not retro walk.

• **Choose the right shoes.** Avoid stiff-soled shoes that don't bend. "Walking shoes" have flexible soles and stiff heel counters to prevent side-to-side motion. But for normal terrain, any comfortable, cushioned, lightweight, low-heeled shoes will do.



## 14 Keys to a Healthy Diet

Developing healthy eating habits isn't as confusing or as restrictive as many people imagine. The first principle of a healthy diet is simply to eat a wide variety of foods. This is important because different foods make different nutritional contributions.



Secondly, fruits, vegetables, grains, and legumes foods high in complex carbohydrates, fiber, vitamins, and minerals, low in fat, and free of cholesterol should make up the bulk of the calories you consume. The rest should come from low-fat dairy products, lean meat and poultry, and fish.

You should also try to maintain a balance between calorie intake and calorie expenditure that is, don't eat more food than your body can utilize. Otherwise, you will gain weight. The more active you are, therefore, the more you can eat and still maintain this balance.

Following these three basic steps doesn't mean that you have to give up your favorite foods. As long as your overall diet is low in fat and rich in complex carbohydrates, there is nothing wrong with an occasional cheeseburger. Just be sure to limit how frequently you eat such foods, and try to eat small portions of them.

You can also view healthy eating as an opportunity to expand your range of choices by trying foods—especially vegetables, grains, or fruits—that you don't normally eat. A healthy diet doesn't have to mean eating foods that are bland or unappealing.

The following basic guidelines are what you need to know to construct a healthy diet.

**1** Limit your total fat intake. Fat should supply less than 30% of your total daily calories. Limit your intake of fat by having a semi-vegetarian diet. Choose lean meats, light-meat poultry without the skin, fish, and low-fat dairy products. In addition, cut back on vegetable oils and butter—or foods made with these—as well as on mayonnaise, salad dressings, and fried foods.

**2** Limit your intake of saturated fat. This is the kind of fat, found mostly in animal products, that boosts blood cholesterol levels and has other adverse health effects. It should supply less than one-third of the calories derived from fat.



**3** Keep your cholesterol intake below 300 milligrams per day. Cholesterol is found only in animal products, such as meats, poultry, dairy products, and egg yolks.

**4** Eat foods rich in complex carbohydrates. Carbohydrates should contribute at least 55% of your total daily calories. To help meet this requirement, eat plenty of fruits and vegetables and six or more servings of grains (preferably whole grains) or legumes daily. This will help you obtain the 20 to 30 grams of dietary fiber you need each day, as well as provide important vitamins, minerals, and phytochemicals (plant chemicals essential to good health).

**5** Avoid too much sugar. Besides contributing to tooth decay, sugar is a source of "empty"

calories, and many foods that are high in sugar are also high in fat.

**6** Make sure to include green, orange, and yellow fruits and vegetables—such as broccoli, carrots, cantaloupe, and citrus fruits. The antioxidants and other nutrients in these foods are regarded as increasingly important in helping protect against developing certain types of cancer and other diseases. Eat five or more servings a day.

**7** Maintain a moderate protein intake. Protein should make up about 12% of your total daily calories. Choose low-fat sources.

**8** Eat a variety of foods. Don't try to fill your nutrient requirements by eating the same foods day in, day out. It is possible that not every essential nutrient has been identified, and so eating a wide assortment of foods helps to ensure that you will get all the necessary nutrients. In addition, this will limit your exposure to any pesticides or toxic substances that may be present in one particular food.

**9** Limit your sodium intake to no more than 2,400 milligrams per day. This is equivalent to the amount of sodium in a little more than a teaspoon of salt. Cut back on your use of salt in cooking and on the table; avoid salty foods; check food labels for the inclusion of ingredients containing sodium.

**10** Maintain an adequate calcium intake. Calcium is essential for strong bones and teeth. Get your calcium from low-fat sources, such as skim milk and low-fat yogurt. If you can't get the optimal amount from foods, take supplements.

**11** Try to get your vitamins and minerals from foods, not from supplements (with the exceptions listed below). Supplements cannot substitute for a healthy diet, which supplies nutrients and other compounds besides vitamins and minerals. Foods also provide the "synergy" that many nutrients require to be efficiently used in the body.

**12** Consider taking supplements of the antioxidant vitamins E (200 to 800 IU daily) and C (250 to 500 milligrams daily). Even if you eat a healthy diet, it's unlikely you will get these amounts of E and C. Also consider taking a basic daily multivitamin/mineral supplement, especially if you are a woman of child-bearing age (who needs extra folic acid, a B vitamin) or over age 60 (because of decreased nutrient absorption by the body).

**13** Maintain a desirable weight. Balance energy (calorie) intake with energy output. Eating a low-fat diet will help you maintain—or lower—your weight, as will regular exercise.

**14** If you drink alcohol, do so in moderation. That is one drink a day for women, two a day for men. A drink is defined as 12 ounces of beer, 4 ounces of wine, or 1.5 ounces of 80-proof spirits. Excess alcohol consumption leads to a variety of health problems. And alcoholic beverages can add many calories to your diet without supplying nutrients.

## The Wellness Guide to Preventive Care

A recent government study showed that more than half of all Americans do not receive many of the important preventive services they need—that is, immunizations, screening tests for early detection of disease, and education about healthy habits and injury prevention. Why not?

- Many Americans—44 million—have no health insurance.
- Many people do not get continuity of care. They may have to switch doctors as they switch from one insurer to another, making it hard to keep track of what services they've had.
- Patients may not insist on getting preventive services. They may be confused about which tests to ask for. They may not know that Medicare (and some other insurance plans) covers some of the pricier items, such as mammograms and colonoscopies, as well as the cheaper ones. They may not know that prevention is usually the most economical form of medicine—well worth budgeting for, even if insurance doesn't cover it.
- With tests for some cancers, there's the embarrassment factor. Some people may dread being tested for colon, prostate, or breast cancer and be relieved if the doctor fails to mention it. Some people would rather not know.
- Both doctors and patients may be confused by contradictory recommendations. What should a medical checkup consist of? Does everybody need an annual physical? Should all men get a PSA test? At what age should a woman start having mammograms?
- Doctors may fail to ask patients about smoking and drinking, not to mention exercise habits and diet. Some HMOs don't encourage their doctors to counsel people. Some doctors think their job is to treat illness, not prevent it.
- The watchword among insurers now is cost containment. Yet medical technologies and consumer demand for services are expanding daily. Thus, we all have to make choices. Will patients in a big HMO get more benefit from an additional MRI machine or from having their doctors take time to counsel them about exercise and a heart-healthy diet? The new MRI machine will be easier to justify, in terms of immediate, measurable benefits.

### How about that annual physical?

It used to seem simple: people were advised to undergo a standardized annual or biannual "complete physical." But in the 1980s, at the request of the government, an independent committee of physicians known as the U.S. Preventive Services Task Force reviewed all evidence and evaluated the benefits and drawbacks of common screening tests and came up with recommendations. (A similar group, the Canadian Task Force on Preventive Health Care, does the same work in Canada.) That head-to-toe physical exam has now been discarded for



seemingly healthy people, since it yields too few benefits for its cost. Over the long run, it doesn't pay off in terms of better health and longer life.

Some tests that used to be routinely done, such as chest X-rays, electrocardiograms (EKGs), urine tests, and complete blood counts, are now reserved for people with symptoms or risk factors. In other words, they are not general "screening" tests and are not done routinely in everyone (and as such are not covered in this article).

The U.S. and Canadian Task Forces continue to update and re-evaluate their advice, reviewing thousands of studies every year and consulting hundreds of scientific reviewers.

### **Health care: your role** (Dr. Donnica.com)

You are responsible, in large part, for managing your own preventive care. Your primary-care practitioner should be your partner. If you need any of the tests listed on the chart, ask about them. You should, if possible, have a copy of your test results and records.

There are other important preventive measures not listed on our chart—the kind of common-sense steps that could save millions of medical dollars and prevent injury, illness, disability, and premature death. Here's a checklist:

- Don't smoke, and avoid secondhand smoke.
- Maintain a healthy weight.
- Get regular exercise. Brisk walking for just half an hour every day can be a big factor in weight control and in staying healthy.
- Choose a diet low in animal fat and sodium, and rich in fruits, vegetables, whole grains, and low-fat or nonfat dairy products. Eat at least two servings of fish a week.
- Keep alcohol consumption moderate: no more than one drink daily for a woman, two drinks for a man. If you are a heavy drinker, seek counseling, and cut back or quit.
- Do self-exams of your breasts or testes, as well as skin.
- Fasten seat belts, see that kids ride in proper restraints, and obey the law. Drive sober and defensively.
- Brush and floss to prevent dental disease.



Medical experts may disagree about a lot of things, but they all agree that good health depends on improved access to and increased use of preventive services.

## A test you don't need

Increasing numbers of readers ask us for the lowdown on the so-called full-body CT scan—a flourishing industry these days. It has even been featured on *Oprah*. *Symptomless people are signing up for these tests—not covered by medical insurance—at a cost of about \$1,000. For most people, results are nil, unless you count a commodity called "peace of mind." But peace of mind is really not something a full-body scan can deliver. And if it could, how often would you have to get one?*

According to the American College of Radiology, the full-body scan is not the right way to screen for cancers of the breast, prostate, colon, or lung—at least not without follow-up tests. It cannot spot high blood pressure or diabetes. The American Cancer Society discourages it as a waste of money, and a poor substitute for the tests listed below.

Furthermore, if the scan does find anything suspicious, you may simply be subjected to more (sometimes invasive) tests—and it may well turn out to be a false alarm. Instead of peace of mind, you get anxiety.

Finally, the FDA worries about needless exposure to radiation from a test that's unlikely to do you any good.

Someday there may be one magic test that will accurately detect anything and everything. But the full-body scan is definitely not it.

## Preventive Services for Healthy Adults

These are the major screening tests (that is, routine tests for people without symptoms) and adult immunizations. Our advice is based largely on the recommendations of the U.S. Preventive Services Task Force. Most HMOs and Medicare cover these services; fewer traditional insurers pay for them. Infants, children, and pregnant women need other kinds of preventive care not described here.

### Blood pressure measurement (to detect hypertension)

**Who needs:** All adults.

**How often:** Once every 2 years for those with normal blood pressure.

**Comments:** More frequent monitoring for those with readings of 130/85 or higher.

### Cholesterol measurement

**Who needs:** All adults.

**How often:** Once every 5 years. More often if total or LDL ("bad") cholesterol is high, HDL ("good") is low, and/or you have risk factors.

**Comments:** Those at high risk for heart disease need medical advice about life-style changes and possibly drug therapy.

### Pap smear (for early detection of cervical cancer)

**Who needs:** All women with a cervix, starting at age 18, or earlier if sexually active.

**How often:** If 3 annual tests are normal, then once every 3 years. More often if you smoke or have multiple sex partners or other risk factors.

**Comments:** Some experts advise that women who have never had an abnormal result can

stop being screened after age 65.

### **Breast cancer screening (mammography)**

**Who needs:** All women 50 and over; those 40-49 should discuss risk factors with a doctor.

**How often:** Annually. Medicare reimburses for it.

**Comments:** Clinical breast exams are also important—consult your doctor.

### **Colorectal cancer screening (fecal occult blood test, sigmoidoscopy, colonoscopy)**

**Who needs:** Everyone 50 and over; earlier for those at high risk.

**How often:** Occult blood test annually; sigmoidoscopy every 5 years or colonoscopy every 10 years.

**Comments:** Digital rectal exam and X-ray with barium enema may also be done. Medicare now pays for colonoscopy. .

### **Prostate cancer screening (prostate specific antigen, or PSA, test; and digital rectal exam, or DRE)**

**Who needs:** Blacks and men with family history, DRE and PSA starting at age 40. For others, DRE, and possibly PSA, starting at 50.

**How often:** DRE annually; PSA on professional advice.

**Comments:** Usefulness of PSA screening for all men remains controversial.

### **Diabetes screening (fasting blood glucose test)**

**Who needs:** Everyone 45 and older; earlier for those at high risk.

**How often:** Every 3 years.

**Comments:** Blacks, Hispanics, Asians, Native Americans, obese people, and those with a strong family history need more frequent screening, starting at age 30. .

### **Thyroid disease screening**

**Who needs:** Women 50 and over; those with high cholesterol or family history of thyroid disease.

**How often:** On professional advice.

**Comments:** Routine screening remains controversial. Talk to your doctor about risk factors.

### **Chlamydia screening**

**Who needs:** Women 25 and younger, if sexually active.

**How often:** Annually, or more often.

**Comments:** Men and women of any age who are at risk for STDs (chlamydia, gonorrhea, syphilis, and HIV) should be tested.

### **Glaucoma screening**

**Who needs:** People at high risk: those over 65, very nearsighted, or diabetic; blacks over 40; those with sleep apnea or family history of glaucoma.

**How often:** On professional advice of eye specialist.

**Comments:** Many eye specialists advise screening all adults every 3-5 years, starting at age 39.

### **Dental checkup**

**Who needs:** All adults.

**How often:** Every 6 months, or on professional advice.

**Comments:** Should include cleaning and exam for oral cancer.

### **Tetanus/diphtheria booster**

**Who needs:** All adults.

**How often:** Every 10 years.

**Comments:** People over 50 are least likely to be adequately immunized.

### **Influenza vaccine**

**Who needs:** Everyone 50 and over, people with lung or heart disease or cancer, and others at high risk.

**How often:** Annually, in autumn.

**Comments:** Even healthy younger adults can benefit and should consider getting the shot.

### **Pneumococcal vaccine**

**Who needs:** Everyone 65 and over, and others at high risk for complications.

**How often:** At least once.

**Comments:** Effective against most strains of pneumococcal pneumonia; lasts at least 5-10 years.

### **Rubella vaccine**

**Who needs:** All women of childbearing age.

**How often:** Once.

**Comments:** Avoid during pregnancy.

### **Hepatitis B vaccine**

**Who needs:** All young adults, as well as adults at high risk.

**How often:** On professional advice.

**Comments:** All newborns should be vaccinated.

### **Chickenpox vaccine**

**Who needs:** Anyone who has never had chickenpox.

**How often:** Once. But above age 13 it requires two shots.

**Comments:** Not recommended for pregnant women or those with compromised immunity.

## Stress: Why you have it and how it hurts your health

By [Mayo Clinic staff](#)

You've got a big presentation in an hour, but you've hardly had a chance to prepare. Urgent e-mails keep popping onto your display screen, each one sending a stab of anxiety through your chest. As minutes tick by, you search frantically for slides and handouts, knowing your boss will summon you any second. Meanwhile, your heart races and your head pounds.

Modern life is full of time pressure and frustration. In other words, it's stressful. Racing against deadlines, sitting in traffic, arguing with your spouse — all these make your body react as if you were facing a physical threat. This reaction gave early humans the energy to fight aggressors or run from predators. It helped the species survive.

Today, instead of protecting you, it may, if constantly activated, make you more vulnerable to life-threatening health problems. Fortunately, though, you can develop skills to avoid some stressors and limit the effects of others. The payoff includes less fatigue, more peace of mind and — perhaps — a longer, healthier life.



### What is the stress response?

Often referred to as the "fight-or-flight" reaction, the stress response occurs automatically when you feel threatened. Your pituitary gland, located at the base of your brain, responds to a perceived threat by stepping up its release of adrenocorticotrophic hormone (ACTH), which signals other glands to produce additional hormones. When the pituitary sends out a burst of ACTH, it's like an alarm system going off deep in your brain. This alarm tells your adrenal glands, situated atop your kidneys, to release a flood of stress hormones into your bloodstream. These hormones — including cortisol and adrenaline — focus your concentration, speed your reaction time, and increase your strength and agility.

### How stress affects your body

After you've fought, fled or otherwise escaped your stressful situation, the levels of cortisol and adrenaline in your bloodstream decline. As a result, your heart rate and blood pressure return to normal and your digestion and metabolism resume a regular pace. But if stressful situations pile up one after another, your body has no chance to recover. This long-term activation of the stress-response system can disrupt almost all your body's processes, increasing your risk of obesity, insomnia, digestive complaints, heart disease and depression.

- **Digestive system.** It's common to have a stomachache or diarrhea when you're stressed. This happens because stress hormones slow the release of stomach acid and the emptying of the stomach. The same hormones also stimulate the colon, which speeds the passage of its contents. Chronic stress can also lead to continuously high levels of cortisol. This hormone can increase appetite and cause weight gain.

**Immune system.** Chronic stress tends to dampen your immune system, making you more susceptible to colds and other infections. Typically, your immune system responds to infection by releasing several substances that cause inflammation. In response, the adrenal



glands produce cortisol, which switches off the immune and inflammatory responses once the infection is cleared. However, prolonged stress keeps your cortisol levels continuously elevated, so your immune system remains suppressed.

In some cases, stress can have the opposite effect, making your immune system overactive. The result is an increased risk of autoimmune diseases, in which your immune system attacks your body's own cells. Stress can also worsen the symptoms of autoimmune diseases. For example, stress is one of the triggers for the sporadic flare-ups of symptoms in lupus.

- **Nervous system.** If your fight-or-flight response never shuts off, stress hormones produce persistent feelings of anxiety, helplessness and impending doom. Oversensitivity to stress has been linked with severe depression, possibly because depressed people have a harder time adapting to the negative effects of cortisol. The byproducts of cortisol act as sedatives, which contribute to the overall feeling of depression. Excessive amounts of cortisol can cause sleep disturbances, loss of sex drive and loss of appetite.
- **Cardiovascular system.** High levels of cortisol can also raise your heart rate and increase your blood pressure and blood lipid (cholesterol and triglyceride) levels. These are risk factors for both heart attacks and strokes. Cortisol levels also appear to play a role in the accumulation of abdominal fat, which gives some people an "apple" shape. People with apple body shapes have a higher risk of heart disease and diabetes than do people with "pear" body shapes, where weight is more concentrated in the hips.
- **Other systems.** Stress worsens many skin conditions — such as psoriasis, eczema, hives and acne — and can be a trigger for asthma attacks.

### Individual reactions to stress

Your reaction to a specific stressor is different from anyone else's. Some people are naturally laid-back about almost everything, while others react strongly at the slightest hint of stress and most fall somewhere between those extremes. Genetic variations may partly explain the differences. The genes that control the stress response keep most people on a fairly even keel, only occasionally priming the body for fight or flight. Overactive or underactive stress responses may stem from slight differences in these genes.

Life experiences may increase your sensitivity to stress as well. Strong stress reactions sometimes can be traced to early environmental factors. People who were exposed to extreme stress as children tend to be particularly vulnerable to stress as adults.

### Reducing the effects of stress

Stress develops when the demands in your life exceed your ability to cope with them. It follows, then, that you can manage stress by:

- Changing your environment so that the demands aren't so high
- Learning how to better cope with the demands in your environment
- Doing both

Here are some helpful techniques:

- **Look after your body.** To handle stress, your body requires a healthy diet and adequate rest. Exercise also helps, by distracting you from stressful events and releasing your nervous energy.
- **Learn to relax.** It's the polar opposite of the stress response. Deep-breathing exercises may put you in a relaxed state. Follow these steps:
  1. Inhale through your nose to a count of 10. As you inhale, your upper abdomen should rise — not your chest.
  2. Exhale slowly and completely, to a count of 10.
  3. Repeat five to 10 times. Try to do this several times every day, even when you're not feeling stressed.

If you have persistent trouble relaxing, consider taking up meditation or studying yoga or tai chi, Eastern disciplines said to focus your mind, calm your anxieties and release your physical tension. Therapeutic massage may also loosen taut muscles and calm frazzled nerves.

- **Shift your outlook.** In many cases, simply choosing to look at situations in a more positive way can reduce the amount of stress in your life. Step back from the conflict or worry that's put you in knots and ask what part of it is troubling you most. Are you afraid of losing face? If so, would it really be that bad? Are you angry or frustrated to the point of losing self-control? If so, is your reaction out of proportion? Take a break, talk to someone close and get a different perspective on your troubles.
- **Get help.** On your own, you may have limited success trying to change the habitual patterns of thought and behavior that trigger your stress response. Psychiatrists, psychologists and licensed clinical social workers are trained to help you break free of these patterns.

## Meeting the challenge

Stress management requires continuous practice as you go through life and deal with change — which often comes unexpectedly. Even if you take everyday frustrations in stride, your stress response can still surge up when you find yourself dealing with something big, such as illness, job loss or bereavement.

Your body's fight-or-flight reaction has strong biological roots. It's there for self-preservation, even if it's not much help in a demanding job or a stormy relationship. If stress is getting the better of you and you fear its long-term effects, don't be afraid to seek help. You may not find a quick or permanent fix, but in time, you'll recognize the signs that pressure is building and learn the best ways to lighten the load.

## Community Resource Network Human Services Database Kentucky and Indiana



A Data Base That Helps You When You Need Help! Just enter [www.crndata.org](http://www.crndata.org) and click on Human Services.

The Community Resource Network (CRN) is a group of non-profit organizations, individuals and government agencies who share a belief that both access to information and the tools to use and understand it are primary components of community improvement agenda.

- CRN is made possible by the : Annie Casey Foundation, Seven Counties Services, Inc., Metro United Way, Kentuckiana Regional Planning and Development Agency, Louisville Free Public Library, Jefferson County Public Schools, Metro Louisville.
- The system is currently set up to retrieve social services available in the community primarily used by social services available in the community primarily used by social services providers for information and Referral purposes.

You will need access to a computer with Internet capability. If you do not have one at home you can contact the CMR Leadership Institute at 502-587-6500 and make an appointment to come in and use one of their computers or go to the Louisville Free Public Library.

If you are unable to locate the assistance you need using this web site you can speak to a referral specialist by calling Metro United Way's First Call system. First Call is open 24/7. Residents of Southern Indiana may also contact info link of Southern Indiana.

### **First Call:**

877-566-4968  
502-566-4968

### **Info Link:**

502-566-4968 Clark/ Floyd County  
877-566-4968 Harrison County