CPASS

# Personal Assistance Services

## for Individuals with Serious Psychiatric Disabilities

Louisiana CPASS Program
Louisiana Department of Health and Hospitals
Office of Mental Health

Prepared by
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The curriculum to train Personal Assistants has two elements: a competency or skill development component and a didactic or knowledge development component. The skill development components include Connecting, Coaching, Collaboration, and Managing Crises. The knowledge development component is a web-based curriculum entitled *Personal Assistance Services for Individuals with Serious Psychiatric Disabilities*.

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## Contents

## Introduction of the Louisiana CPASS Program

The goal of the Louisiana CPASS program is to provide community-based personal assistance services to individuals with psychiatric disabilities. Personal Assistance Services (PAS) are most commonly used for people with physical disabilities, and involves providing assistance with daily activities that the person has difficulty with because of the effects of the disability. This service will help people; however, it is not widely available at this point in Louisiana (or in most other states) for individuals with psychiatric disabilities.

Mental health services in Louisiana, like in the rest of the country, have changed from being primarily institutionally based to being more community based, and the PAS program is an outgrowth of these changes. Historically, mental health services in Louisiana started with the opening of a wing of Charity Hospital in New Orleans in 1820 to treat people with mental illnesses. Mental health services were to remain institutionally based for more than a century. In 1959, there were over 9,000 individuals in Louisiana hospitalized with mental illness. Changes that influenced the shift to community care include the development of antipsychotic drugs in the 1950s, which made it possible for more people to be treated in the community. Also, several federal laws helped to change policy. The passage the Community Mental Health Act, in 1963, gave funding to the states to set up community clinics. The Medicaid Act, in 1965, and the Supplemental Security Income law, in 1971, provided funds that helped individuals to live in the community. By 1972, Louisiana had 25 community mental health centers around the state.

There have been a number of state budgetary problems that have made this transition difficult, and Louisiana has tried to make the community-based system work even though funding has not always been adequate.

In 2001, a Consumer Task Force made the following suggestions to the Secretary of the Louisiana Department of Health and Hospitals (DHH). This Task Force looked at issues for individuals with many different kinds of disabilities, and made the following recommendations:

1. Improve community-based Medicaid services for adults and children with mental health issues.
2. Increase community-based supports for adults and children with mental health issues through state funding.
3. Develop a plan for people with disabilities or chronic illnesses to have access to direct support staff who are adequately trained and compensated to provide long-term care supports.
4. Develop agreements and contracts with organizations or individuals to conduct workshops on the idea of self-determination, direction, and responsibility for individuals with disabilities and the people who provide support for them.

Based on these recommendations, the main ideas of the Personal Assistance program were developed through money awarded to Louisiana by the Federal Government in 2003. Several partnerships were developed with the Office of Mental Health (OMH) to aid in the creation of the program. These include:

1. The Disability Services and Supports System (DSSS) Consumer Task Force
2. Personal Assistance Self-Direction Project Steering Committee
3. Meaningful Minds of Louisiana (MML)

4. National Alliance for the Mentally Ill (NAMI-LA)
5. Mental Health Association of Louisiana (MHAL)
6. Louisiana Statewide Independent Living Council
7. The Extra Mile

The purpose of the program is to provide services to individuals with psychiatric disabilities that are controlled and shaped by them. What this means is that the individual receiving the services is able to decide not only what services he or she receives, but who provides the services, and the manner in which those services are provided. It is expected that the result of such a program would be that individuals would be more satisfied with services, as well as, better quality of life, increased community-involvement, fewer trips to the hospital, and fewer days in the hospital. The ultimate goal is increased independence.

Doing a good job as a Personal Assistant takes a lot of knowledge and skill. This manual is designed to teach you what you need to know in order to do a good job for your main supervisor, who is the individual with the disability. (See organization chart on page 38). You will be hired, however, by an agency which will also provide some guidelines and rules for you to follow, and which will provide some training about their expectations and policies. This curriculum does not include those rules and guidelines. It is important that you inform yourself about them when you get hired so that you can do the best job possible.

The manual is divided into two parts. The first part will give you the information and tips you may need to understand who you will be working with and how you should be working together. The second part will teach you some basic skills that you will need to do the work.

# Understanding the History and Origins of PAS

## The History of Mental Health Services

For many years, the treatment of mental illness in the United States was built on several major ideas. It was believed that serious mental illnesses, like schizophrenia, bipolar disorder (also known as manic-depression) and severe depression, were lifelong conditions from which people were not expected to recover. Further, it was believed that the best places to treat people with these conditions were in long-stay institutions. Because these illnesses were thought to be incurable, the best outcome that could be hoped for was that people would experience relief from some of their symptoms.

Over the years, some of these beliefs have changed. Most people with diagnoses of serious mental illness no longer live in institutions, but instead in various kinds of community settings. However, the idea that people can't get better is changing very slowly. Even when they are living in the community, people diagnosed with serious mental illness usually live lives very different from other people because of lack of opportunities. Most of them don't work, and they often live in supervised settings of one sort or another (like group homes and halfway houses). It continues to be widely believed that people with serious mental illnesses are not capable of living independently, working, or integrating into the community on the same basis as people without disabilities (Chamberlin, 1984).

Coercion (the use of force) continues to be a feature of the mental health system. People diagnosed with mental illnesses may be required to enter a hospital, even when they don't want to, or to take medication, even when they are living outside of an institution, because there are laws requiring them to do so. The main reason for such laws is the widespread belief that people diagnosed with serious mental illnesses are not capable of knowing what they need or of making reasonable decisions about their own treatment. New services are needed that are not based on these old myths. Personal Assistance Service (PAS) is one such new service.

## The History of Personal Assistance Services (PAS)

The late 1960s and early 1970s was a time of great social upheaval, which led to people working for changes that were important to them. The inspiration for much of this activism was the civil rights movement, which started in the mid-1950s and led to the passing of the Civil Rights Act of 1964. Inspired by this example of what could happen when people stood together to fight inequality, prejudice, segregation, ignorance, and racism, other oppressed groups took notice and began to organize and fight for their rights. One such group was people with physical disabilities. They wanted to be treated like everyone else, to live outside of institutions, to go to school or college, to work at a job, to live as independently as possible, and to become active participants in their local communities. This movement became known as the "disability rights movement" (Johnson, 1983).

At the same time, another group of people who were psychiatrically labeled (or mentally ill) began to organize. Their goals were almost exactly the same as those of the disability rights movement. This new movement had many names, including the psychiatric survivor movement and the mental health consumer movement (Chamberlin, 1990; Deegan, 1992).

Before these movements began, community services for people with severe disabilities of all kinds were bleak or non-existent. Many people with disabilities were institutionalized as young children. Those who became disabled as young adults were often forced to live in nursing homes or other institutions, where they could receive the "nursing care" they needed. Home-based services did not yet exist, and the traditional medical "wisdom" of the time assumed that these individuals could never live outside a medical facility and certainly not live independently in the community.

Two of the key leaders of the disability rights movement were Ed Roberts in California and Judy Heumann in New York (websites: *Ed Roberts, father of…*, n.d.; *A discussion with Judy Heumann…,* n.d.). Ed Roberts became paralyzed at the age of 14 from polio. He wanted to attend the University of California in Berkeley. He applied and was accepted; he just never mentioned that he was a quadriplegic who required the use of a ventilator to help him breathe, and who slept in an iron lung at night. He and a few other disabled students were finally admitted and were housed in the college infirmary while attending classes. These students then fought for the right to live in ordinary university housing, and eventually developed what became the first independent living center in the country, in Berkeley, California.

At the same time in New York City, Judy Heumann, who also had polio and used a wheelchair, managed to get a college education and become a certified teacher. She was told that she couldn't teach in the New York City school system because she used a wheelchair (schools did not have ramps or any accessible features at the time). She sued the Board of Education, which was ordered to issue her teaching license. With a few other disabled people, she then went on to found Disabled in Action in New York City.

The Berkeley Independent Living Center, started by Ed Roberts and his colleagues, provided consumer-directed services for people with disabilities. The philosophy was that disabled people themselves knew best what they needed. Judy Heumann's group, Disabled in Action, was an organization that focused on demonstrations as a way to bring about change and win rights for disabled people. Eventually, Judy and Ed joined forces and activism and services were both seen as equally important.

There are now nearly 500 Independent Living Centers (ILCs) across the nation, creating a brand new service model in an empowering environment run by and for people with disabilities. Independent Living Centers (ILCs) are non-profit, consumer-controlled, community-based, non-residential agencies that provide services and advocacy by and for people with all types of disabilities. Independent living means having control over one's life, and being able to make important decisions toward that end. ILC philosophy includes concepts such as the right to fail and the dignity of risk, right to self-determination, and maximizing self-reliance.

- Dignity risk/right to fail means that it's all right to take chances, even if one might not succeed, just the way non-disabled people do.
- Right to self-determination means that essential life choices should be made by the disabled person, based on his or her own values, beliefs, and aspirations.
- Self-reliance means that, even though a disabled person may need assistance with some things, he or she should be as independent as possible.

ILCs assist people with disabilities to achieve their self-identified goals through peer counseling and skills training. They also provide a way to fight politically, known as "advocacy," and teach people to advocate for themselves and others. ILCs often serve as a strong consumer voice on a wide

range of local, state, and national issues of importance to people with disabilities. ILC staff and consumers work in the community to educate others about disabilities and to debunk the myths and stereotypes surrounding disability. They also work on all levels to assure physical and programmatic access to housing, employment, education, transportation, recreational facilities, and health and human services. ILCs have been instrumental in the development of personal care attendant (PA) services, which are now referred to as PAS or personal assistance services (National Council on Independent living, 1988b).

PAS developed from the recognition that a new type of home-based personal assistance was needed to replace many services that people used to think could only be done by nurses. People with disabilities began talking with each other, sharing their experiences and ideas for a more consumer-driven system for necessary personal services. Together, they came to realize that a trained lay person, hired and trained by the consumer, could perform many of the functions that were previously seen as nursing services. Eventually, personal assistance became a Medicaid-funded service, because it cost substantially more to keep a person in a nursing home than it did to have a person live independently with support through personal assistance. This change in funding came about because of demands by people with disabilities and their organizations (National Council on Independent living, 1988a).

People in the disability rights movement often had their own biases, prejudices, and hierarchies, which meant that people with some disabilities—particularly psychiatric and intellectual disabilities—were largely left out of the movement. In 1992, the Rehabilitation Act of 1973 (the federal law that, among other things, funds ILCs), was amended to require that all ILCs had to be cross-disability, which meant they had to serve all types of disabilities.

One of the last groups to be included in ILCs was persons with psychiatric disabilities. This group of people was unfamiliar to many ILC staff, many of whom did not understand their problems and didn't see the similarities between the experiences of people with physical and psychiatric disabilities. Providing PAS to mental health consumer/survivors was a radical idea for many of the ILCs, which primarily served people with mobility disabilities (that is, people in wheelchairs). ILCs lacked understanding of this particular set of disabilities, and lacked the staff with the knowledge and understanding to provide services to them. Even though many of the issues and needs for these consumer/survivors were the same (such as access to housing, employment, etc.) the emotional and thinking problems for persons with psychiatric disability were difficult to understand. Some ILCs overcame these problems to serve individuals with serious psychiatric disabilities (Deegan, 1996–1997). However, even today, many ILCs still do not really understand the needs and issues of this community. This situation is why you are in training to become a PAS provider, so that these useful services will be available to this population.

The mental health consumer movement developed along parallel lines to movements by people with physical disabilities (such as wheelchair users, people with visual and or hearing impairments), and by people with developmental disabilities (commonly called "mental retardation"). In all cases, these groups seek to define their own needs and reject the idea that other people can speak "for" them. All seek to live independent lives, to make their own decisions, and to be valued despite their differences. This is often referred to as "empowerment" (Wilkinson, 1996–1997; Chamberlin, 1984).

The mental health consumer movement is organized locally, regionally, and nationally, as well as, internationally. In Louisiana, a statewide group, Meaningful Minds, is in formation, while a self-help

program, BRIDGES, is offered in many parts of the state. Meaningful Minds is a consumer-operated self-help group. Their focus is on giving a voice to consumers of mental health services in policymaking, and in providing advocacy that represents the consumer viewpoint.

BRIDGES (Building Recovery and Individual Dreams and Goals through Education and Support) began in Tennessee in 1995. It is a program that provides education and support to mental health consumers, teaching them in a structured program about recovery and wellness, and then providing ongoing mutual support groups. BRIDGES came to Louisiana and is run in cooperation with the Mental Health Association of Louisiana.

The Louisiana Department of Mental Health also funds a consumer liaison position in each of the ten regions of the state—this is a part-time job, filled by a consumer, which provides a consumer voice into departmental decision-making.

## Current Trends in Mental Health

Recent developments in the provision of mental health services are the concepts of rehabilitation and recovery. Rehabilitation means that people diagnosed with serious mental illnesses can participate in community life, with the assistance of programs that help them to define their goals and the methods to reach those goals. In services based on rehabilitation, people with serious mental illnesses get opportunities to make their own choices about where they will live, and what kinds of work or education they want to pursue. Such services are usually more flexible than traditional mental health services, and are concerned with people's real-life needs. While people may also use medical services (such as seeing a psychiatrist or psychologist, or taking medication), these services are different from rehabilitation services (Farkas, Gagne, Anthony, & Chamberlin, 2005).

Recovery means that people diagnosed with serious mental illnesses are seen as capable of making their own life choices. They can live independently in the community, and can function as a member of the community, on an equal basis to their peers without disabilities. In order to do so, people may need some supports that are flexible and based on the person's own choice. It is important to note that recovery does not necessarily mean that a person's symptoms go away—it may mean, instead, that people learn new ways of coping with their symptoms that make them less intrusive and interfere less with their lives. The concepts of rehabilitation and recovery overlap one another in many ways (Fisher & Ahern, 1999).

These developments have meant that there have been enormous changes in the mental health care system, which was once focused almost exclusively on large mental institutions. The growth of community mental health centers, clubhouses, supported work programs, mobile treatment teams, and similar community-based efforts have transformed the mental health delivery system. It should be noted, however, that coercion continues to be part of many community-based mental health systems, and that people are often required to take medication or other treatments over their objections, even when they are living in community settings.

Unfortunately, the old ideas of incurability and permanent disability are still widely believed, despite these changes. Widespread myths about people with mental illnesses are found in the general public, the media, and political leadership. Most people continue to believe that anyone diagnosed with a serious mental illness is never going to get better. Further, it is commonly believed that individuals with mental illnesses are dangerous (when only a few may be), and therefore that constant supervision is required. Such beliefs lead to the further notion that people with serious

mental illnesses cannot be trusted to make good decisions about their lives, and therefore, that it is necessary to have laws to force them to be in treatment or to take medication. These ideas are often referred to as "stigma," and lead to discrimination against people who have, or are thought to have, mental illnesses. Stigma and discrimination contribute to the difficulties that people have in reintegrating into the community (Deegan, 1988).

From experience, people diagnosed with mental illnesses have developed self-help/mutual support as a valuable way of helping one another, which is distinct and different from professionally-run services. This does not mean, of course, that people diagnosed with mental illnesses can't also participate in and benefit from the services offered by doctors, social workers, and other professionals, but points out that people benefit both from the academic knowledge of professionals and the experiential knowledge of their peers (Fisher, 1996–1997, 1998).

## History and Origins of PAS: Multiple Choice Questions

1. Where most people in Louisiana with mental illness were usually treated before the 1950s?

   ☐ a. At a community mental health center
   ☐ b. In a hotel
   ☐ c. At a state hospital or Charity Hospital
   ☐ d. None of the above
   ☐ e. c only

2. Where most people with mental illness are usually treated today?

   ☐ a. At a community mental health center
   ☐ b. In a hotel
   ☐ c. At a state hospital
   ☐ d. In a general hospital
   ☐ e. None of the above

3. How have ideas about improvement and recovery for people with mental illness changed?

   ☐ a. Used to think that recovery was possible but now people do not think so
   ☐ b. Used to think that recovery was impossible but now many people think it is possible
   ☐ c. A few people used to think that recovery was possible but now many people think it is possible
   ☐ d. Used to think that recovery was impossible to get better and some people still think it is impossible
   ☐ e. b, c, and d

4. What are some widely held beliefs about people with mental illnesses?

   ☐ a. Dangerous
   ☐ b. Needs constant supervision
   ☐ c. Can't be trusted to make decisions for self
   ☐ d. Can't hold a job
   ☐ e. All of the above

5. How are consumer groups useful to people in promoting recovery?

   ☐ a. Providing self-help
   ☐ b. Giving mutual support
   ☐ c. Share similar experiences
   ☐ d. Educate one another
   ☐ e. All of the above

6. What is meant by "empowerment"?

- ☐ a. Have the right and ability to make decisions
- ☐ b. Turn on the electricity in the house
- ☐ c. Take the power mower out and cut the grass
- ☐ d. Is something you can give someone else
- ☐ e. None of the above

7. What is a personal assistant?

- ☐ a. A good listener
- ☐ b. A paraprofessional
- ☐ c. A person who works for a person with a disability
- ☐ d. A person who works under the direction of a person with a disability
- ☐ e. All of the above

# Understanding Your Job: Part 1
# What are personal assistance services (PAS)?

## What Distinguishes PAS from Other Services and Supports?

In order to provide personal assistance services (PAS) to people with psychiatric disabilities, it is important to distinguish PAS from other services and supports that a person with a psychiatric disability may use. Some of the important features of PAS, which distinguish it from other services, are:

1. The provider of services is a paraprofessional (someone with training but without a special academic degree). Being a paraprofessional is an important role that can assist the person with a disability, and also has the potential for the provider to further develop his or her career if he or she wishes. The PAS provider is chosen by the person with a disability ("the PAS user"). This is a very different relationship from a case manager or a home health aide, who reports to an agency and to whom the person with the disability is a client.

2. The purpose of a personal assistant (PA) is to perform (or help the person with the disability perform) those things that the person is unable to do him/herself, or has difficulty with, because of his/her disability. PAS, therefore, is centered around activities of daily life (of which some examples are washing, housekeeping, cooking, shopping) rather than centered around "treating" aspects of the disability.

3. PAS services are provided under the direction of the person with the disability. This is probably the aspect of PAS which makes it most different from other kinds of services. The person with the disability, in PAS, is not in the client role; instead, he or she is the person who determines what services are provided and the ways in which they are performed (in other words: your "boss") (Independent Living Research and Utilization, n.d.).

### You Are the "Provider of Services" (in other words, "The Employee")

A PAS provider is a paraprofessional providing services in the employer's own home (or other community settings). The provider works under the direction of the employer. The PAS provider is responsible, first and foremost, to the person with the disability for whom he or she works.

### The Employer Is the Individual Consumer You Are Working For

A PAS employer is a person with a (psychiatric) disability, who wishes to receive assistance with daily activities that he or she experiences difficulties with because of disability. The employer defines those things that he/she may need assistance with, and then defines the ways in which he/she wishes to receive this assistance.

### The Services

PAS providers may be asked to help with a wide range of services, depending on the needs of the user, the process of the employer or the individual consumer you are working for and the provider agency. PAS providers mutually define what is needed and how it will be provided. A small set of examples of the kinds of services that could be provided by PAS include assistance with:

- meal planning, shopping, or cooking

- waking and daily personal hygiene
- organizing or taking medication
- keeping doctors' or other similar appointments
- organizing and paying bills
- organizing and performing normal housekeeping
- controlling symptoms (through reminders or pointing out certain behaviors)

Whatever the specific services may be, they are worked out through discussions between the provider and the employer.

Because PAS was developed originally to serve people with physical disabilities, it may, at first, be difficult to see direct comparison between services provided to people with such disabilities (for example, assistance in transferring from a bed to a wheelchair) and those provided to people whose disabilities are psychiatric in nature. However, in both cases, the role of PAS is to provide services that the person needs in order to function in the community. (Eckels & Brown, 1997).

## What Are the Limitations of PAS?

PAS is not a substitute for services provided by various kinds of professionals and paraprofessionals within the mental health or social service delivery systems. A PAS provider is *not*:

- a social worker
- a job coach
- a crisis intervention worker
- a psychiatrist, psychologist, or therapist
- a vocational rehabilitation counselor

While the provision of PAS is an entry-level job, this in no way devalues the very important roles that the PAS provider can fill. A PAS provider is someone who enhances the abilities and the quality of life of a person with a disability, by enabling that person to function more normally in a variety of community roles. It is precisely because PAS is provided in an informal, non-professional, peer to peer manner that it is so valuable. A person with a psychiatric disability may need the services of a variety of mental health and social service professionals, but it is the interaction between the PAS provider and the employer which may make it possible for him or her to utilize the professional services he or she may need.

For example, suppose that the PAS employer or the individual consumer you are working for, is experiencing great difficulty in waking up at a reasonable hour and starting the day (for many people with psychiatric disabilities, this problem may be increased by some of the negative effects of psychiatric medications). Suppose, as well, that the employer really wants to get a job, and is working with a vocational rehabilitation counselor toward that end. In such a situation, the employer might instruct the personal assistant on the techniques that would be most helpful to insure that he or she was awake and dressed by nine each morning. Without that assistance, the employer might never make it to the appointments with the counselor, and might, therefore, not be successful in the goal of getting and keeping a job.

There is a difference between receiving professional services which are built on assumptions about expertise, and those provided by personal assistants. The person using professional services is in the role of a client, while the professional is the expert. The "client" is expected to follow the

directions of the professional. In most (although not all) situations, the client visits the professional in his or her office. Even when the professional comes to the client's home (for example, a visiting nurse or mobile crisis team), the professional/client roles still apply.

In PAS, in contrast, the roles are somewhat reversed. The PAS employer or the individual consumer you are working for, is seen as the "expert" on his or her own disability, and on what particular things are helpful (or not helpful) in particular situations. The employer guides the provider, through discussion and negotiation, so that the provider can understand the employer's needs and the ways in which he or she wishes assistance.

## What Are the Values and Principles of PAS?

Working with people with disabilities can be extremely rewarding. It can also be extremely challenging and stressful. However, such a job can be a powerful force for change as well—both for the PA and the person with the disability who is being helped. Personal Assistance Services (PAS) assists people with disabilities to live with dignity and helps them become more independent. They are therefore less dependent on others at home, and better able to participate fully in the community. Your main focus as a personal assistant is to help individuals set and achieve their self-determined goals.

This model of services is very different from traditional mental health services. It is based on a set of values and principles differ from those that guide the medical model. In the PAS model, the focus is on the individual self-defined goals and needs of the person receiving the services. This is not to say that the PAS model is better than the medical model, but to point out that they have different basic principles.

In the medical model of mental health services, people are called "patients." Patients are seen as sick, broken, or chronically ill, and therefore may be considered incapable of making their own decisions, setting their own goals, living independently, and/or participating in their communities of choice. Patients are told the only way to get better is to follow the doctor's orders, especially to take medications as prescribed. Often, normal feelings and actions, such as anger, frustration, sadness, grief, or questioning the system, may be considered part of the patient's illness or pathology.

In the PAS model, on the other hand, the individual is not a patient, but a "consumer" who directs the process. People with disabilities are not seen as sick or broken. Having a disability (such as a mental illness) is seen as something that the individual can learn to live with, utilizing various services and supports. Independence can be achieved through skills training, peer support, and other services as determined by the individual. The purpose of PAS services is to assist the individual to achieve a much more fulfilling life than one that consists of just being warehoused in day programs and halfway houses.

Self-determination is a key concept. For example, a self-determining consumer approaches the subject of medication very differently from the passive consumer in the medical model, described above, who just follows the doctor's orders. A self-determining consumer will want a doctor he or she feels comfortable with, who will listen and work in partnership with the consumer. The role of the personal assistant may be to help the consumer who wants more information about medication to do research, so he or she can make informed decisions. The personal assistant might also help

the consumer prepare for doctors' appointments by assisting him or her to make a list of questions to ask the doctor. The approach is focused on helping in a way that fosters empowerment.

You, the personal assistant, play a very important part in the lives of the people with disabilities, who hire you. Your role is complex and can often be confusing. Having a clear set of values and principles to guide you in your work can provide a way to check what you are doing so that you understand both the scope and the limitations of your role. Your job as a PA has many aspects, which may include a facilitator, an advocate, a teacher, a role model, a mentor, a networker, a resource-gatherer, a skills trainer, an interpreter, a mediator, and an informal counselor in the lives of those you work with.

You will work closely with the consumer/employer, who hires you, to figure out what his or her goals are, both large and small. Together you will figure out what skills and supports he or she will need to be as independent as possible. You have an opportunity to greatly impact on how he or she experiences life. The relationship you create is the key to making way for empowerment, recovery, and hope. This is especially important because, often, despair, darkness, hopelessness, and rage may be all that the person remembers in life. It is important for people who are in the process of recovering from mental illnesses to be able to discuss their experiences with other consumer/survivors and eventually share them with people they can trust. Developing trust may be the most difficult hurdle to cross.

The work is not easy, and it can be challenging and frustrating. But with these services, consumer/employers are the ones who set the pace, determine what goals they hope to achieve, and set their priorities. Your main job is to support the individuals you work for on their journey to empowerment, recovery and self-determination. It is important to become aware of the literature of recovery and empowerment; so that you can fully understand that recovery can be a long and difficult road with many curves, boulders, detours and potholes. In other words, recovery is a process, not a place (Massachusetts Association of Independent living Centers, 1992; Bradley, 1996).

**Guiding Principles and Beliefs***

- Belief that MH consumers (PAS-employers) can recover from mental illness, with proper skills and community supports.
- Belief that MH consumer (PAS-employers) belong in the community, not in segregated settings.
- Belief in new non-medicalized service models that offer ways to increase community independence.
- Belief that MH consumers (PAS-employers) know themselves and their needs best, and are able to set and attain personal goals.
- Belief in a recovery/resilience-oriented approach, where MH consumers (PAS-employers) are seen as more than the sum of their disabilities.
- A true commitment to these rehabilitation and recovery concepts at all organizational levels, particularly the top leadership, is necessary to implement programs and services using new PAS Model.

**Key Values**

- Valuing Others
  Affirms a common humanity with the people they support, recognizing that they share similar aspirations, dreams, hopes and goals; we are more similar than different.
- Valuing Self
  Affirms a common humanity with the people they support, recognizing that they share similar aspirations, dreams, hopes and goals; we are more similar than different.
- Valuing Helping
  Belief in the importance of compassion, empathy, caring, commitment and cooperation. Recognizes that the administrative priorities of human service organizations sometimes conflict with providing support and find ways to emphasize the support priorities whenever possible.

* Note: These principles are taken from a document developed by The Human Service Research Institute, which developed a set of national skills standards for direct service workers, entitled "Direct Support Work: Values & Vision."

## Understanding Your Job, Part 1: Multiple Choice Questions

1. What are the services that personal assistants offer:

   ☐ a. Home based
   ☐ b. In community
   ☐ c. Funded by Medicaid
   ☐ d. Not medical
   ☐ e. None of the above

2. PAS Services are:

   ☐ a. Chosen by Community Mental Health Center that is in charge
   ☐ b. Chosen by person with disabilities who is in charge
   ☐ c. Helps the person with disabilities do things that he or she is unable to do
   ☐ d. Works with the disabled person's own home or other community settings
   ☐ e. b, c, and d only

3. The work of PAS may include if needed which of the following:

   ☐ a. Meal planning or cooking if needed
   ☐ b. Organizing the taking of medications if needed
   ☐ c. Organizing and helping to pay bills if needed
   ☐ d. Shopping if needed
   ☐ e. All of the above

4. What the personal assistant is not:

   ☐ a. A social worker or a psychologist
   ☐ b. A psychiatrist
   ☐ c. A crisis intervention worker
   ☐ d. A vocational rehabilitation counselor
   ☐ e. All of the above

5. The following are not guiding principles and values of PAS:

   ☐ a. The PAS provider is the expert in the relationship and thus needs to make the major decisions for the individual with the psychiatric disability

   ☐ b. PAS recognizes that all individuals have the same hopes, dreams and aspirations

   ☐ c. PAS uses only medical services to help individuals with psychiatric disabilities (e.g., clinics, physicians, nurses etc).

   ☐ d. a and b

   ☐ e. b and c

   ☐ f. a and c

## Understanding Your Job, Part 2
## How people recover and the idea of resilience: Helping people in their life's journey

### Who Has Mental Illness?

Mental illness can affect persons of any age, race, religion, or income. Further, mental illnesses are not the result of personal weakness, lack of character, or poor upbringing. Such persons may need help with housing, vocational rehabilitation, income assistance, and personal assistants, such as yourself, can help them to reclaim their lives again.

### What Are People Recovering From?

They are recovering from not only their illness and disability but from a loss of sense of self, a loss of connectedness, a loss of meaning, a loss of power, and a loss of hope (Spaniol, Gagne & Koehler, 1998). Many of the living situations in which the person has lived (such as state hospitals and board and care or nursing homes) were unable to provide opportunities to make independent choices. Now such persons are relearning how to make wise decisions on how to live their life they way they would like to live it.

### Resilience and Recovery

Resilience means that people can not only survive the ups and downs of life but can go on to thrive as well. Adults bring their personality and experience to a tough situation. The more hopeful and optimistic a person can be, the easier it is to be resilient. Research has also shown that even people who have been very disabled from serious and persistent mental problems can and do improve, live independently, and recover across time. This is why your work is so important.

Things that seem to get in the way of being more resilient are: being negative or pessimistic about people, life, and the future, self-blame, wishful thinking, giving up, daydreaming, pretending that the problems are not real or not accepting what has happened. Activities that seem to increase resiliency are the following: talking with friends, accepting that change is part of life, taking action, moving toward one's goals, keeping things in perspective, maintaining a hopeful outlook, writing in a journal, meditation, walking in nature, and taking better care of yourself.

### What Is Mental Illness All About?

In this job, you will be working with people who have been diagnosed at one time with a "mental illness." Mental illness and physical illness are often discussed as being two different things but they are not. Any illness is caused by stress interacting with physical vulnerabilities acquired or inherited by the person. Illnesses of any kind tend to make the person have problems with the kinds of roles a person plays such as a worker, a student, a husband or wife, or a mother or father. Illness also can interrupt the ability of the person to take care of him or herself such as doing ordinary things like the dishes, or doing the grocery shopping. Then tasks like planning, or deciding, or reading other people's facial expressions may become difficult. And sometimes the brain plays tricks on the

person by making a person's thoughts sound like voices, or makes the person incredibly sad, or suspicious of others. This means that if the person looks able to function but is not, the benefit of the doubt needs to be given to him or her and not to automatically assume that the person is being lazy or mean on purpose.

Sometimes, when a person is recovering from a mental illness, they have difficulty determining if what they are feeling is a normal feeling (mad, sad, glad, or afraid) and whether or not they are feeling symptoms of their illness. Your observations and comments can be helpful with this puzzle. Simply by asking them if this feeling they are experiencing might be a normal feeling or not will help him or her figure out this natural confusion.

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## Different Types of Illnesses

### Depression

Depression is not just feeling a little blue or out of sorts about a situation. Feeling blue can arise out of conflict with people, the loss of someone important, or other changes in life. Real depression, as a problem, makes an individual feel worthless, helpless, guilt-ridden, often blaming him or herself for everything that is going wrong in their world. Such persons may have problems with food (eat too much or too little), may have problems with sleep (too much or too little), lose all interest in any activities, have difficulty in concentrating, and are either too agitated or too slow in their movements. Some people experience suicidal thoughts or make plans to kill themselves.

### Mania

Mania is the opposite of depression, in which a person shows poor judgment, becomes overly excited, shows embarrassing behaviors, and often is unable to think clearly. Sometimes people speak incredibly fast and jump from one idea to another. Sometimes feel very grandiose (king of the world) and become agitated. Mania rarely occurs without a swing to depression, which is called bipolar disorder. It should be noted that the symptoms of bipolar disorder vary among individuals.

### Schizophrenia

Schizophrenia is a difficult illness to have because it changes the way a person thinks, feels and acts. The disorder is really a group of illnesses, the symptoms of which may include hallucinations, delusions, speaking or behaving in ways that do not make much sense, and withdrawal. Hallucinations include seeing, hearing, tasting, or smelling things that others do not see, hear, or smell. Hearing things is the most common. It is usually a voice (often quite mean spirited) that constantly criticizes the person and there seems to be no "off button." Delusions occur when a person misinterprets experience, such as feeling persecuted, tricked, spied upon, or thinks that the TV or songs are speaking directly to him or her. Often such persons will stop taking care of themselves, show little emotion, speak little, and appear unable to make plans. Some of these reactions may be due to drug effects and others may be due to a depression on top of the schizophrenia.

### Anxiety Disorders

Anxiety disorders come in various forms. A panic disorder makes a person feel suddenly like they are full of terror, fearful, and are experiencing impending doom. The person experiences shortness of breath, feels his or her heart pounding, chest pain, choking, and fear of losing control.

Phobias have to do with a specific anxiety about a certain place or situation which is to be avoided. For example, social phobia has to do with the person being afraid of speaking in public or other social situations. Obsessive-Compulsive Disorder means that someone is obsessed with an idea which causes great anxiety, and is compelled to do something about it to relieve the anxiety (such as fearing germs and continually washing one's hands). Posttraumatic Stress Disorders stem from a traumatic event(s) such as being personally attacked, serious accident or injury, the sudden unexpected death of a family member or friend, war, rape, etc. Sometimes a person relives the situation because of something in the everyday world that reminds them of it or invades their dreams, or there are flashbacks. Remembering the traumatic event may cause an individual with PTSD physical stress and so the person tries to avoid things that might remind themselves of this event. They may feel that their lives will be cut short and have very little interest in day to day activities. They may startle easily. Other symptoms include numbness or agitation.

## Special Subgroups

### Older Adults

Some of the people you may work with as a personal assistant may be older adults (over 65). Some of them are people who have been diagnosed as mentally ill earlier in life, while others may be newly diagnosed. Sometimes other problems, such as physical illness, the large number of medications that older persons often take, grieving over lost loved ones, being socially isolated, or being unable to access services to help with any of these problems may lead to an older person being diagnosed with a mental illness, when this is not really what the problem is. For example, an older person who appears angry and suspicious may be dealing with an unrecognized hearing loss, and the "symptoms" may go away when the person is fitted with a hearing aid! Therefore, it is especially important when working with this population to make sure these kinds of problems are ruled out before a diagnosis of mental illness is made.

In aiding individuals with mental illness, special needs arise for older adults, such as problems with memory, which may mean information to be repeated. If the person appears to have lost interest in life, you might try challenging him or her with things that are interesting, such as with crossword puzzles or playing games, or simply helping him or her to explore new interests, activities, and relationships.

Helping older adults regain or keep fulfilling and productive lives is one of the challenges of PAS services. Developing a supportive relationship with an older individual is pretty much the same as developing a relationship with anyone else, except that it may take a bit longer to really get to know each other and to find the right pace for your interactions.

### People Who Use and Abuse Drugs and Alcohol

About 50 to 60% of persons with mental illness also use street drugs or too much alcohol. People sometimes use drugs or alcohol because they think it relieves some of their symptoms, but often drug and alcohol abuse can also increase the number of times a person can get sick again. They may go into the hospital more often, show more violence, end up in jail or become homeless, as well as be exposed to HIV or other infections. One of the big problems is that there are two separate systems of care for mental health and substance abuse. When the person has both at the

same time he or she needs attention to both problems and it is often difficult to get the two systems to work together.

One of the best things a personal assistant can do is to assist the person to develop friendships, to talk about the problem, and to have more skills and pursue goals. The person may benefit from being linked to Alcoholics Anonymous (AA) or Narcotics Anonymous (NA), but it is not the role of the personal assistant to refer people to these groups. It may put you in a very difficult situation if you believe that the person you are working for has a drug or alcohol problem that he or she is not recognizing or dealing with. If you are worried about this, talk to the person you are working with (the consumer) about your concerns. Ask if the individual would be willing for you to connect him or her with the agency which hired you, in order to talk to someone there about the issue.

If the person does not give you permission, but starts to do things which are dangerous to him or herself, or to you, because of the substance abuse, then you need to contact the agency supervisor and ask for assistance. This is one of the situations in which you are allowed to violate confidentiality, so it is important that you think there is a dangerous situation, and not just that the person is doing things you don't approve of.

**People Who Sometimes Think about Suicide**

Thinking about killing oneself happens to most everyone at some time in life. Most people do not act upon these thoughts. But suicide is still the 10th leading cause of all deaths in America. For young white males, it is the second leading cause. When a person has a mental illness, life can sometimes seem to be unbearable. Drugs and alcohol may increase these feelings. If the person is impulsive, and also feels hopeless, then a personal assistant should be alerted for warning signs.

These signs include abrupt changes in personality, sudden mood swings, risky behaviors, decreased interest in school or work, inability to concentrate, and loss or lack of friends.

Listen to hear if the person has a lethal weapon, or for specific plans (such a jumping off the bridge). Hopelessness, loss of an important person, obsession with death, giving away prized possessions, or suddenly making a will are strong indicators that the person is becoming very serious. Most people who commit suicide have given warning of their intentions. Many are ambivalent and will try to seek help. Not all people who try suicide are depressed or have other forms of mental illness. If someone has been depressed, the period of highest risk is when the individual is beginning to feel better. Asking someone if they intend to commit suicide actually lowers the risk.

Sometimes such persons require hospitalization to increase the chance of having them in a safer environment, but even these institutions cannot guarantee a 100% safe place if the person is determined to commit suicide. If the personal assistant hears a discussion with plans for suicide being mentioned, or sees a lethal weapon, then he or she should talk to the person and suggest that he or she talk soon with his or her therapist, social worker, or other trusted person. Once again, you as a personal assistant can be put in a very difficult situation if you think the person you are working for may be contemplating suicide. This is another situation where it might be necessary for you to violate a person's confidentiality, because his or her life may be in danger.

## More Strategies That Might Help a Person Get Better

People who are struggling with any kind of illness or significant problem are human beings who could use your support, skills, and knowledge to help themselves become more independent citizens in the community. One of the ways you can help is to be enthusiastic and cheerful about the person, their future, and your job. This attitude will go a long way to help increase the person's self esteem and abilities.

Reclaiming a life primarily involves the person's own efforts toward independence. It involves an active self, taking stock, relying on oneself, finding supports, learning to love, increasing self-esteem, tolerance, acceptance, building on reality, better coping, self-monitoring, spirituality, seeing a process, and reclaiming hope (Spaniol, Gagne & Koehler, 1998).

The first thing you will need to do is to develop a positive relationship with the person you are working for by treating him or her with kindness, respect, and dignity so that you become a real companion. Next, you should spend some time to discover the person's interests and goals. Each person, including you, brings certain strengths and abilities to the situation. As the person grows stronger in their sense of self, you will discover even more strengths and abilities. Make sure that the person feels safe enough to be able to express his or her own needs and choices. To promote this sense of safety, the person needs to know that you will keep his or her information confidential (with certain life threatening or legal exceptions). You as the paraprofessional and the person to whom you are providing services need to write up a statement which will designate what kind of information you can share and with whom you can share it. If you and the person are dealing with a crisis situation, it would help you both if you both developed a plan together to help stabilize the situation. Your primary job will be to help the person with a variety of living tasks depending on his or her needs and desires, such as housekeeping, food preparation, laundry, shopping, managing medications, and other tasks outlined in a personalized care plan. Independent living means having opportunities to participate in all aspects of community living. It also means that a person makes decisions and takes responsibility for his or her own actions. Independent living also means that a person can control and direct his or her own life and can take risks even if it means a failure.

PAS can be instrumental in helping an individual not only stabilize but to begin to recover. It should be noted, however, that recovery from mental illness is a two steps forward one step back process. You can help make a big difference in someone's life if you can help the person reach his or her goals by listening to his or her hopes and dreams, respecting his or her culture and religious or spiritual life, and encouraging him or her to regain as much independence as possible. Connecting persons to the community is a great way to help them become a bigger part of it. Supporting a person when they indicate interests in their family members, church groups, native healers, neighbors, community colleges, libraries, and social clubs has been shown to be very helpful.

Other ways you can help this person to feel whole again is to help him or her to take more and more control over his or her life again; to help the person understand and accept the problems as part of a journey he or she is taking, and to look forward to the future. Having hope that things will eventually get better, feel better, and be better is a very critical part of the recovery process from these illnesses. Expect that he or she will become stronger and better. Expect that he or she has the capacity to learn, grow, and change, because no matter how sick he or she became, he or she still has many strengths which have allowed him or her to continue to try and live his or her life. Expect that your employer or the individual consumer you are working for will be the one to

make decisions about his or her own life. This kind of work is richly rewarding. You are providing a relationship, which is the best way to help a person who is struggling. Your work is part of your employer's support system, which may also include clinicians in the local service system, and the use of medications if needed and desired.

**Supportive Psychotherapy**

Supportive psychotherapy has been designed to help a person struggling with unwanted symptoms and a disruption of life to talk with someone about this intrusion into his or her life. Supportive therapies can not only help such a person grieve over lost opportunities, but to get on with adult development, such as becoming more independent and managing the day-to-day requirements of taking care of oneself.

**Medications**

Medications for the person's symptoms may be helpful or may not be. It depends on many things: whether or not the symptoms are really reduced, whether or not the person's system can handle them, and whether or not these pills produce big side effects. One of your jobs will be to help your employer or the individual consumer you are working for, begin to understand if medication is helpful or not. If not, encourage your employer to talk again with his or her doctor about the way the medication makes him or her feel from the inside out. Sometimes it takes many tries to find the right combination. For many people but not all, these pills can be helpful. Some factors that change the way a person reacts to pills are smoking, street drugs and alcohol, and big changes in exercise levels or eating.

You can help the individual consumer you are working for, take his or her medications more safely by teaching him or her pattern for taking pills. Pharmacies now include a set of directions with each prescription, which should be read before taking each new medication. First, the person should read the label to make certain that these particular pills are meant for that person at that time of day and how many should be taken. If correct, have the person learn to get a saucer or a napkin on which to pour out the correct number of pills. This action keeps the pills clean and from rolling onto the table or floor. Check the label again to make doubly sure this is the right time to take the medications and the correct amount. Have a glass of water or juice to take the medication. Some pills require a full stomach, while others are to be taken before meals. Knowing what medications are being taken and how to take them will reduce much confusion. There are pill boxes which can be filled once a week with the days marked on the box which might also be helpful. Of course, you will assist your employer or the individual consumer you are working for with medication (or anything else) only to the extent he or she wants your assistance.

There are four main categories of medications which are used for symptom management: antipsychotic, antimanic (known as mood stabilizers), antidepressant, and antianxiety. Scientific study has shown that all treatments for mental illness, including medication management, should be combined with rehabilitation in order to achieve and maintain recovery. As a personal assistant, it may be necessary to help the individual with mental illness maintain their medication regime. For more information on medications themselves please see Appendix A.

Antidepressants, plus being able to talk with someone in various types of psychotherapies, appear to be the best combination to give symptom relief and prevent relapse. Bad reactions to these drugs include either excessive sleepiness or insomnia, weight gain, blurred vision, difficulties in

sitting up from a sleeping position, nausea, heartburn, anxiety, agitation, headaches and rashes, and reduced sexual desires.

The person needs to know which pills to take with food, and which should be taken on an empty stomach. Any of these side effects should be reported by the individual to his or her doctor. One of the trickiest drugs for a person to manage are pills called MAOI's (short for a long name, Monoamine Oxidase Inhibitors) such as Nardil (phenelzine), Parnate (tranylcypromine) and Marplan (isocarboxazid). These drugs react strongly and poorly to foods such as cheeses, certain soups, sauces, gravies, and dressings, imported beers, processed meats, sour cream and others (the list is very long and the person should get it from his or her doctor). It is wise to have the person prepare his or her own food so that he or she knows what is in the food he or she is eating. Many over the counter drugs interact poorly with MAOI's, as well such as Sudafed, Vicks, Robitussin, Dimetap, etc. It is always wise to know what is on the list. Sudden headaches, nausea, vomiting, and/or seizures mean a serious reaction exists and the person needs to go to the emergency room of the local hospital. Other antidepressant drugs include the tricyclics and "SSRIs" along with others such as Welbutrin. All drugs have specific dosages and need to be taken on a regular schedule. Individuals are usually started on low doses and worked up to a level best for him or her. If your employer is using several different medications simultaneously, it may be helpful to have a chart which shows all the information including the name of the drug, the dosage, and any special instructions (such as whether to take with food). Overdosing on these drugs can be fatal and should be handled immediately. (A list of these medications and their possible side effects can be found in the appendix.)

Antimania drugs (otherwise known as Mood Stabilizers) and other therapies: If people seem to have gone "off the deep end" many different kinds of help are available, including a safe environment, group therapy, psychotherapy, and medications. Drugs such as Lithium and Tegretol, and other drugs in this group, and sometimes antipsychotics, have been shown to be helpful, but many people discontinue them or go on and off. Episodes of the illness return and the person learns that these episodes get in the way of other things which he or she really wants to do. Other drugs with names such as Depakote, Eskalith and many others also treat these illnesses (a list may be found in the appendix). If the medications help in preventing episodes, the person eventually decides to stay on for a while.

However, Lithium particularly can affect the thyroid, and this is often confused with depression. It can also affect the kidneys, which in turn affect urine and may cause diabetes (too much sugar in the blood). Lithium can also affect the heart, and it can cause a very itchy rash. Other possible bad effects include mental dullness, decreased memory and concentration, headaches, muscle fatigue, shaky hands, weight gain, a metal taste in the mouth, and swelling around the eyes. If a woman on Lithium becomes pregnant it is a very good idea to discontinue this medication, as it has a good chance of hurting the developing baby. A woman, who is pregnant, or planning on becoming pregnant, should discuss this with her doctor. Helping your employer to recognize side effects, and suggesting that he or she talk to his or her doctor will be very helpful. Doctors often have a very hard time telling the difference between bipolar disorder, schizoaffective disorder, and schizophrenia, and the person's diagnoses may switch among all three.

Antipsychotics, plus people to talk with in supportive psychotherapy and other rehabilitation efforts, help people who have been struggling with a psychosis such as schizophrenia. Doctors may use these drugs with many other disorders as well. Antipsychotic medications actually seem to

work in about 60% of cases to reduce hallucinations and delusions and to help reduce new episodes of these illnesses. However, there are many side effects with which a person must cope. These side effects range from abnormal involuntary movements (meaning that the person taking these medications may have muscles which move out of their control) such as mouth jaw, face, and neck. Another reaction makes a person feel compelled to be in motion all the time (fidgeting, rocking, pacing, and restlessness). Yet, another reaction may cause a person to have a tremor (for example, shaking hands), which shows up when resting, as acting rigid in walking, or rolling an imaginary pill between a thumb and the first finger. Some medications which help control these additional problems include Cogentin, antihistamines such as Benedryl, Beta Blockers such as Propranolol, or others such as Amantadine. Other problems may include diabetes, weight gain, low blood pressure, feeling sleepy all the time, heart problems, eyes sensitive to light, allergic rash, problems with sex, and yellowing of the skin. Caffeine and other over the counter drugs can interfere with these medications as well. The best advice for a personal assistant is to be observant and urge the person to report any of these side effects to his or her doctor. (A list of these drugs may be found in Appendix A)

Antianxiety drugs are provided for people who have not only an anxiety disorder but also to people with many kinds of illnesses. Most common are benzodiazepines ("benzos"). These drugs help to reduce the feelings of anxiousness, but they have some side effects as well, including drowsiness, and difficulties walking and driving. Sometimes people experience increased appetite, weight gain, and headaches. These pills can be abused, and stopping them abruptly can cause withdrawal problems such as sleeplessness, headaches, feeling faint, blurred vision, sounds in the ears, fevers, diarrhea, and shakiness. Antacids and food slow down the effectiveness of these pills. Antihistamines and several other drugs (barbiturates, antipsychotics, and antidepressants) also can reduce anxiety. Some of these drugs are Xanax, Atavan, BuSpar, and Effexor (a list of such drugs may be found in Appendix A).

## Other Available Services

Besides medications, many individuals will also use various kinds of mental health, health, and other community-based services. In Louisiana, as in most other states, a person has the right to refuse services and medications if they so choose. This is part of the principle of self-determination, as discussed earlier, and means that individuals are learning to take responsibility for themselves. These services are called, collectively, community-based support services.

You, as a member of the team working together with your employer, will work together to promote and sustain improvement in his or her quality of life and independence. The person with whom you are working is the key member of the team, and his or her wishes are the most important.

### Community Mental Health Centers (CMHC)

Community Mental Health Centers (CMHC) are the primary professional service which is assisting in the process of improvement and recovery. CMHCs have many different types of people working for them, including case managers, nurses, psychologists, social workers, and physicians trained in psychiatry. This group at the CMHC may offer medications, supportive psychotherapy (also known as counseling), help with entitlements (financial benefits), housing, getting jobs or

further education, and increasing social skills. CMHCs may also work with the families and children of their primary clients, if this is appropriate and desired.

### Other Community People

If your employer wants your assistance, you may also help him or her talk with other important people in his or her life. This group might include people such as landlords, other social agencies, self-help groups, family members and friends. Sometimes, you may be able to help the individual consumer you are working for, resolve small problems in this way, before they escalate into crisis situations.

### Other Health Care Supports

Your employer may have not received other health care services such as dental care, medical check-ups, and hearing tests. Because these services may have been ignored for years, many people who have been diagnosed with mental illness die 10 to 15 years earlier than people who have not been so diagnosed. It is important to try to help the person to get the medical and dental services he or she may want. This may mean helping him or her to find out what medical coverage he or she has and what medical practitioners will take this insurance.

### Natural Community Resources

Like other people, your employer has interests, and part of your job may be to suggest groups in the community to which he or she might want to belong. For example, if the person likes to sing, suggest a church choir; if the person is interested in sports, suggest a local league; if the person is interested in stamp collecting, help him or her to find a stamp club. There are many groups in the community for you and your employer to explore and consider. The more he or she can get out of the house and into the work and fun of a community, the faster he or she will feel more independent and part of his or her community. This part of recovery is for a person to have an increasing number of interactions with people who are totally outside the mental health arena.

### Self-Help and Consumer-Run Services

In 1988, Dr. Pat Deegan, a consumer who was ill for many years and then became a famous psychologist wrote, "First we must recognize that persons with psychiatric disabilities do not 'get rehabilitated' in the same sense that cars 'get tuned up.' Persons …are not passive objects [for] which professionals are responsible for 'rehabilitating.'…We are responsible for our own lives…and we can become responsible agents in our own recovery process" (Deegan, 1988).

People can help one another recover by working together in a variety of self-help settings. There are Drop-In Centers (now called Consumer Resource Centers) which include informal settings where people can gather to find companionship. Many drop-in centers offer a combination of naturalistic supports (for example, people sitting in a living room setting together, drinking coffee, socializing, and discussing matters of common interest) and more formal supports (such as structured self-help discussion groups). Consumer Resource Centers provide spaces where people who often have nowhere else to socialize, can feel that they are part of a community of equals. These centers are usually staffed by consumers who are moving along in their own recovery process and want to reach out to others who may not be as far along.

There are also job clubs, which provide opportunities for socializing, as well as classes which teach people to find and keep jobs. These classes include such skills as job searches, résumé writing, and interview role playing, to help a person become employed. Since your employer or the individual consumer you are working for, may not have worked for many years, if he or she wants a job, this kind of help is extremely important.

Sometimes, despite all the various kinds of support available in the community, your employer may have an episode of illness that is so severe and disabling that the treatment staff may decide that he or she needs to be in the hospital. This can also happen if the staff decides the individual has become a danger to self or others. Currently hospital stays usually last only several days. The expectation is that a brief hospitalization is just a temporary setback in the overall recovery journey.

**Medicaid/Medicare Benefits**

There are many government plans which will provide financial supports for persons with serious and persistent disabilities. Your employer will probably be enrolled in one or more of these programs, including Supplemental Security Income (SSI), Social Security Disability Income (SSDI), Medicare, Medicaid, and others. These programs often have complicated requirements, and it can be very confusing for anyone, particularly a person dealing with many other problems, to figure out all the notices he or she may receive in the mail. You can be extremely helpful to the individual consumer you are working for by helping him or her with this paperwork, making phone calls, going to appointments, and the like. People with mental illnesses often become extremely anxious about these programs and their shifting requirements, which is understandable because they affect the person's whole life. A missing check, for example, may mean your employer or the individual consumer you are working for, doesn't have the money to pay rent—this would make anyone anxious! By helping your employer to navigate this "red tape," you can provide a valuable service.

The agency which supervises your work as a personal assistant should have a lot of information about these programs which will help you to explain this to your employer.

## Understanding Your Job, Part 2: Multiple Choice Questions

1. Mental illnesses affect:

- ☐ a. Only people who are weak
- ☐ b. Only people who lack character
- ☐ c. Only people who have poor upbringing
- ☐ d. People of any age, race, religion, or income

2. Resilience means that:

- ☐ a. A person with mental illness will commit suicide
- ☐ b. A person finds hope and grows stronger over time
- ☐ c. A person is unable to use the resources in the environment to help him or herself
- ☐ d. A person is overwhelmed

3. Depression is:

- ☐ a. Just being a little "blue" and "down in the dumps" for a couple of days
- ☐ b. A major mental illness which makes a person feel hopeless, worthless, and quilt-ridden
- ☐ c. An illness which makes a person feel overly happy and optimistic
- ☐ d. A tough economic situation in the 1930s

4. Schizophrenia:

- ☐ a. Means the person has 2 personalities
- ☐ b. Is a serious illness that disrupts a person's thinking and feeling
- ☐ c. Makes a person have pneumonia
- ☐ d. Always means the person is violent and unpredictable

5. Older adults with mental illness may:

- ☐ a. Be acting unusually because of too many medications or other physical ailments
- ☐ b. Need social groups
- ☐ c. May need a hearing aid
- ☐ d. All of the above

6. People who abuse drugs and/or alcohol :

- ☐ a. Do not go to jail or the hospital
- ☐ b. Are at higher risk for problems such as HIV, violence, or homelessness
- ☐ c. Do not need to go to AA or NA
- ☐ d. Never raise their voices

7. Studies of suicide show that:

- ☐ a. The 10th leading cause of death in America
- ☐ b. Reveal that no one contemplating suicide tells others of the plans
- ☐ c. No risky behaviors occur beforehand
- ☐ d. Is not affected by drugs and alcohol

8. A personal assistant can help someone reclaim a life by the following behaviors:

- ☐ a. Developing a positive relationship
- ☐ b. Tolerance and acceptance
- ☐ c. Enthusiasm and cheerfulness for the job
- ☐ d. All of the above

9. There are 4 main types of medication designed to help people manage their symptoms of mental illness:

- ☐ a. Supportive psychotherapy
- ☐ b. Antipsychotics, antimanics, antidepressants, & antianxiety drugs
- ☐ c. Cocaine and marijuana
- ☐ d. None of the above

10. Services and activities for people struggling to recover from serious mental illnesses can include the following:

- ☐ a. Drop-In Centers & Community Support Services
- ☐ b. Natural Community Supports such as singing groups and baseball leagues
- ☐ c. Community Mental Health Centers
- ☐ d. All of the above

## Understanding Your Job: Part 3
## What other important information do you need to know to do the job of a personal assistant?

### Confidentiality

Confidentiality is one way of showing respect and supporting the right of the consumer to privacy. Put in another way, confidentiality is the agreement between you and your employer to keep private information that you come to know about him or her.

Confidentiality is a very important value and ethic. As a personal assistant, you must absolutely guard and protect the individual's confidentiality. You are not to share any information about his or her mental health or medical conditions without your employer or the individual consumer you are working for giving you direct permission to share it. Gossip and busybody information is not relevant to an individual's recovery, and has no place in a helping situation.

Confidentiality is one of the most important bridges you can build to establish trust with your employer. Consumers may have been through terrible experiences in treatment settings. They may have suffered physical, sexual, or emotional abuse. Consequently their trust has been violated. It is therefore essential but often difficult to reassure your employer that you will not also violate their trust and reveal personal information. The individual consumer you are working for may be very leery about sharing information, or about you, the worker meeting with their providers without them present. They may even appear paranoid.

People who help others need a certain amount of information in order to do their jobs well. Also, to feel appreciated workers need to know when their efforts have been helpful. The PAS employer, however may not want information of a personal nature conveyed to certain family members or acquaintances. It is strongly suggested that you start a conversation on the topic of confidentiality and trust when you are first employed. Keep in mind that it is also helpful to discuss confidentiality, on an on-going basis, because people's needs and wants regarding confidentiality often change over time. Everyone, not only individuals with mental illnesses change their perspective about confidentiality over time. Having this conversation will help to reassure your employer that you are a peer, but you are also a professional who takes their job responsibilities very seriously. To avoid confusion or misunderstandings, use the Release of Information forms through your agency. These forms will make clear what you can share, who you can share information with and whom you cannot speak to, regarding your employer.

Telling anyone that an individual is getting professional help is a violation of confidentiality if you do not have a "release of information" signed by the consumer you are working for? A release of information gives you permission to share specific information with specific people. This is the law: sharing information when you have no permission to do so is a misdemeanor offense. If you reveal personal information without permission, you will not only likely end your job but you may also put your employer at risk of harm.

Please speak to the agency which hired you to learn the details of its confidentiality policies. It is important to follow all federal, state and local rules/regulations about protecting the private health information of any client or PAS employer.

## Right to Privacy

It is important to remember any information you may have access to in clinical charts, a staff meeting, or through what the consumer says is about important and often intimate issues in another human being's life. If the information you have is not relevant to the tasks you are performing yourself, it is not information you need to do your job.

There are some exceptions which do allow you to violate the individual's confidentiality in certain situations, and it is important that both you and your employer are aware of them.

You may also violate confidentiality if your employer is threatening to commit suicide or to inflict serious bodily harm upon him or her self.

## Ethical Responsibility to Warn

What does an "ethical responsibility to warn" mean? If an individual makes threatening statements about harming another individual, you should report this to your agency immediately. If the threats:

1. Are specifically directed at an individual ( e.g., "I am going to kill John"; not " I would like to kill someone")
2. May cause potentially substantial harm, (e.g., "I am going to run John over" not "John makes me so mad I could throw something at him!")
3. The agency personnel believes there is a very good chance that the person will act upon the threat in the foreseeable future,

The director of your agency may decide that the intended victim should be notified of the threat.

## Developing More Than a Professional Relationship

You may develop a personal or mentoring relationship your employer or the individual consumer you are working for, especially if you have had similar experiences as he or she has had. It is important to remember, however, that the person you are working with is your employer and your first priority is to complete the tasks you are being paid to perform. It is not appropriate to enter into any business relationship with your employer. It is not appropriate, while you have a working relationship, to date the person you are working with, nor to date his or her family members and friends outside of working hours. Usually, although not always, this type of relationship may make your employer uncomfortable and has the danger of making your working relationship tense, awkward and unhelpful. It is important to discuss this issue, if it comes up, in a way that makes it clear that you are not rejecting the individual but that you are acting on a PAS policy and principle.

## Reducing the Probability of a Crisis

At times, difficult situations may arise between you and your employer or the individual consumer you are working for. If this happens, follow these ten steps:

1. Speak clearly and distinctly, calling the individual in conflict by name.
2. Deal with behavior, not personality.
3. Listen carefully and restate what the other person says in your own words.
4. Encourage and make positive statements.
5. Acknowledge honest feedback from the person in conflict even if it is negative.
6. Avoid getting angry over the situation and expressing your feelings about the behavior.
7. Try to reveal the "hidden" feelings behind the behavior by talking about and attempting to understand the causes. (for example, your employer may be upset with someone else or a difficult life situation).
8. Avoid the "silent treatment" (walking away), or withdrawing into silence.
9. Avoid bringing up behaviors and negatives that have nothing to do with the present situation.
10. Strive for a win/win situations by finding things you both can agree on and then build a solution together.

Things to avoid

- Demanding compliance. (that is, demanding that the person "do what you say").
- Giving unreasonable alternatives.
- Double messages (that is, saying one thing but acting like you mean something else).
- Arguing with the individual.
- Interrupting or cutting off the individual in mid-sentence.
- Overriding another staff or agency decision regarding rules and expectations.
- Threatening or intimidating the individual.
- Ridiculing or belittling the person.

## Consumer Rights and Responsibilities

The rights of consumers you work with are protected under federal and state legislation. A few examples of such legislation are the Americans with Disabilities Act, the Fair Housing Act, and the Civil Rights Act, all of which protect the person's civil rights, and the Rehabilitation Act of 1973, which covers employment and education rights (see section on law for more details). Each community mental health center should have a list of consumer rights for individuals receiving any mental health services/treatment there. You should become familiar with the consumer rights in your agency.

## What Is Expected of You as a Personal Care Attendant?

1. Listen to your employer and support him/her in setting the goals for your work.
2. Treat your employer with courtesy and respect at all times.
3. Discuss with your employer how much time you have to schedule with him or her.
4. Arrive on time and in the right place for your appointments. If this is not possible, call and cancel as soon as possible.
5. Do not burden the consumer with your own personal problems.
6. Use your employer's property only with permission from him or her. If you are assisting the consumer to accomplish a task within his or her home, ask for permission before opening a drawer, closet or private space.
7. You are not expected to purchase items for your employer from your own funds. Your employer will budget his or her own funds for this purpose.
8. You may not use physical force to restrain your employer for any reason. In an emergency, dial 911.
9. Report any suspicion of abuse by others to his /her agency as soon as possible.

## What Is Expected of Recipients of PAS Services?

1. Discussing the work schedule of the PAS provider.
2. Instructing the PAS provider on what tasks are desired, and how they should be performed, to help the individual reach his or her goals.
3. Letting the PAS provider know if there are outside appointments that the individual wants the PAS provider to accompany him or her to.
4. Being in the place and at the time the PAS provider is scheduled to meet with the recipient.
5. Budgeting for activities the recipient needs, and giving the provider the money to purchase these items if that is a task assigned to the provider.
6. Never using physical force against the provider.
7. Treating the PAS provider with courtesy and respect at all times.
8. Reporting any abuse by the PAS provider or others to the agency or police as soon as possible.

## Ethics

The PAS program at your agency is under the supervision of a Qualified Mental Health Professional, which means that the supervisor is licensed by the state. The Behavioral Science Regulation Board has a very specific code of ethics. Anyone who is licensed under this Board (which covers most licenses you will encounter in a Mental Health Center) must adhere to the Code of Ethics. Providers are also liable for anyone they supervise who violates the code of ethics, if they have knowledge of the violation. This means that even though you do not have a license, you are covered by the code of ethics.

Ethics help protect consumers and you. Ethics help consumers from being exploited by helpers who may have a role of perceived power. Ethics help us avoid potentially dangerous or compromising situations. Many of the following "rules" help us avoid the pitfalls of confusion about expectations, and misunderstandings which can sometimes ruin relationships. The PAS worker, for example, is there to provide support and assistance to the employer, not to burden the consumer with the PAS provider's personal problems. Ethics also gives everyone a framework within which they can examine their motives when they have to make difficult decisions.

### Ethical Guidelines in Providing a Helping Service

*Always check with your Center for specific policies on these and other ethical guidelines:*

1. Overnight visits of consumers in your home are absolutely not allowed for any reason.
2. Do not engage in any outside relations with any individual introduced to you by the consumer/care giver/family unless directly asked by the consumer to do so.
3. Do not express your opinion in any way to the consumer, family, or friends regarding other professionals/providers such as case manager, therapist, social worker, or family advocate. (This does not mean however, that you shouldn't listen to your employer's opinions of service providers; but you are expected to remain neutral).
4. Do not give or accept substantial gifts from consumers. Do let the individual know at the beginning of your employment that PAS policy/principles state that gifts that cost a lot of money (i.e., set an specific amount like $5–$10 for example, or whatever is appropriate to the region you are in) should not be exchanged between you and the consumer. It may be helpful to explain that you are both on limited budgets it is less stressful to show appreciation of each other verbally or something like a handmade card.
5. Do not enter into a sales agreement or any other business arrangements with consumers.

## Liability/Legal Issues

The last area of special consideration is legal issues. It is impossible to define all legal issues involved in any area of life but a few that are important to follow or discuss with your supervisor are listed below.

1. Do not perform any tasks you were not specifically trained and hired for as an attendant care worker. For example, if you sell Avon products, do not sell them to your employer. If you work in a beauty shop, do not cut clients' hair during an attendant care session. Do not trim nails. Do not perform any household or car maintenance task for your employer that would normally be performed by a licensed or certified individual (i.e. electrician, plumber, mechanic, etc.). You were not hired by your agency to cut hair or sell Avon products. If something goes wrong with the Avon products for example, or with the hair cut or nail trimming, the individual may want to or need to sue someone. Your agency's liability insurance probably does not cover haircuts, use of products or nail trimmings. If you use your own car or your employer's car for transport of consumers, check with your auto insurance to make absolutely sure that you and/or the consumer will be covered in the event of an accident.
2. Never enter a consumer's home without permission, for any reason whatsoever.
3. Do NOT give a consumer over-the-counter medication you have in your pocket or purse, not even Tylenol, stomach aids, antihistamines, or cough drops. You do not have a license to dispense or prescribe medication.

## Understanding Your Job, Part 3: Multiple Choice Questions

1. What are some of the resources available to you as a personal assistant, and to the person who hired you?

   ☐ a. The community library, the internet, local, state and federal government
   ☐ b. Social groups and self help groups
   ☐ c. Family and friends
   ☐ d. Dentists and people who test hearing
   ☐ e. All of the above

2. What are the rights of confidentiality and privacy?

   ☐ a. Secrets that you can tell others about your boss' private or medical information
   ☐ b. Helps build bridges of trust when you tell your boss that you will not tell others about personal information
   ☐ c. Work on a "need-to-know basis with others
   ☐ d. It is a good idea to talk about how you will keep information confidential with your boss
   ☐ e. b, c, d are correct

3. What responsibility do you have to warn others and break confidentiality?

   ☐ a. Your boss makes threats against a specific person
   ☐ b. Your boss threatens substantial harm to a specific person or group
   ☐ c. When there is a good chance that the threat will happen soon
   ☐ d. When you hear or observe child or elder abuse
   ☐ e. All of the above

4. How should the Personal Care Assistant behave?

   ☐ a. Listen and support
   ☐ b. Provide courtesy and respect
   ☐ c. Agree with your boss about the schedule
   ☐ d. Arrive on time
   ☐ e. All of the above

5. How should the employer behave? He or she should do the following:

   ☐ a. Do not ask the employee to spend his or her own money for things the boss needs
   ☐ b. Never use physical force against the employee
   ☐ c. Treat the employee with courtesy and respect
   ☐ d. Report any abuse by the personal assistant
   ☐ e. All of the above

6. The Personal Care Assistant should never:

- ☐ a. Stay overnight
- ☐ b. Express negative opinions of other caregivers
- ☐ c. Accept or give big gifts
- ☐ d. Have sex with the employer
- ☐ e. All of the above

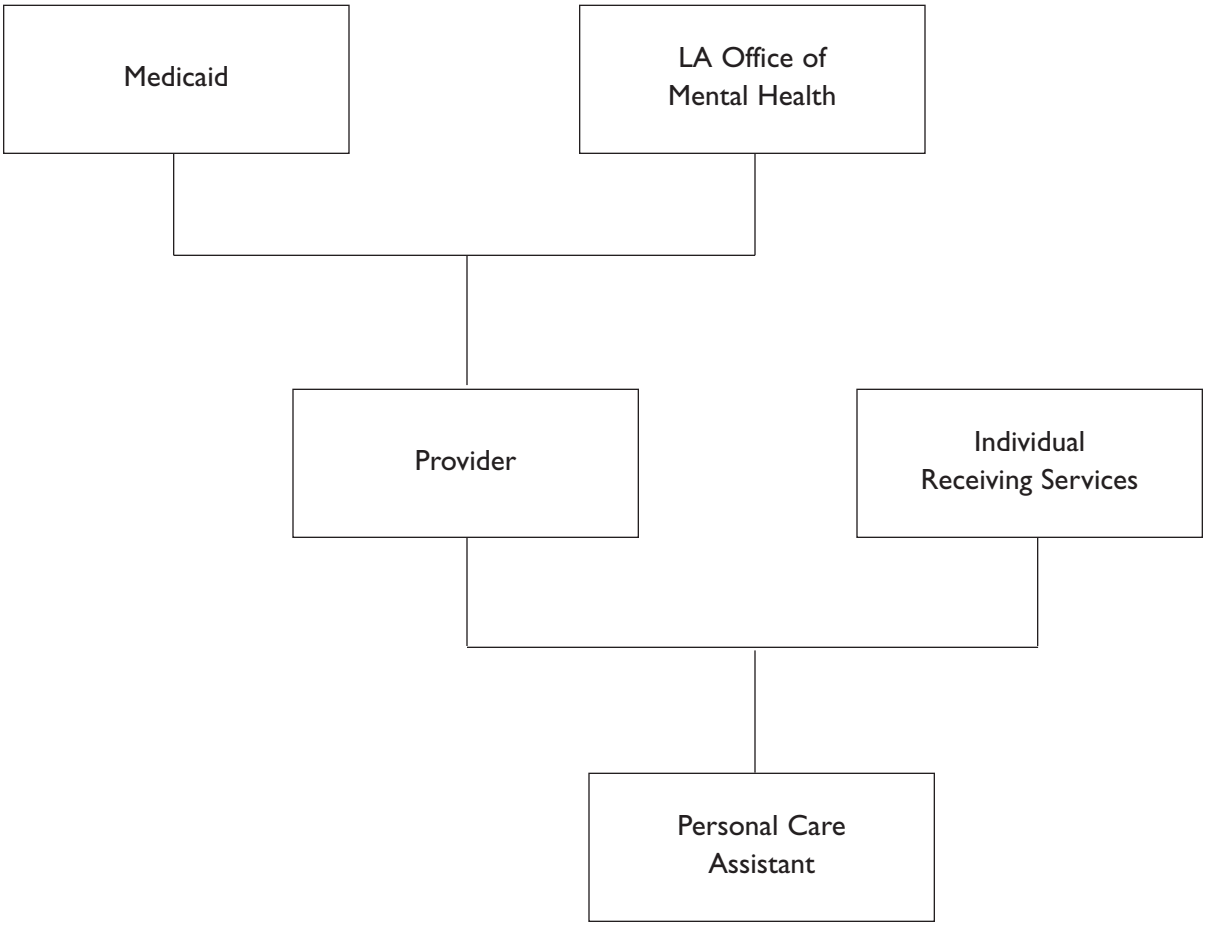
7. The Personal Care Assistant should never:

- ☐ a. Give your employer over the counter medications that you just happen to have
- ☐ b. Take the employer for a ride in your own car unless your insurance policy will cover an accident
- ☐ c. Enter your employer's home without permission
- ☐ d. Do services for which you were trained but which are not in your contract
- ☐ e. All of the above

8. How can you reduce the probability of a crisis?

- ☐ a. Make positive statements
- ☐ b. Deal with behaviors not personality
- ☐ c. Scream and yell to make your points
- ☐ d. Walk away or give the silent treatment
- ☐ e. a and b only

## Organizational Chart for PAS Providers



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# Appendix A — List of Frequently Used Medications

## For Schizophrenia

| Generic Name | 1st Generation Brand Name |
|---|---|
| Chlorpromazine | Thorazine |
| Fluphenazine | Prolixin; Permitil |
| Haloperidol | Haldol |
| Loxipine | Loxitane |
| Mesoridazine | Serentil |
| Molindone | Moban; Lidone |
| Perphenazine | Trilafon |
| Pimozide | Orap |
| Prochlorperazine | Compazine |
| Thioridazine | Navane |
| Trifluperazine | Stelazine |

**2nd Generation Medications**

| | |
|---|---|
| Aripiprazole | Abilify |
| Clozapine | Clozaril |
| Olanzapine | Zyprexa |
| Quetiapine | Seroquel |
| Risperidone | Risperdal |
| Ziprasidone | Geodon |

## For Depression, Bipolar Disorders, Obesssive-Compulsive Disorder, Phobias, Panic Disorders, Bulemia Nervosa, Cocaine Abuse, Chronic Pain

| Cyclic Antidepressants Generic Names | Brand Names |
|---|---|
| Amitriptyline | Elavil |
| Amoxapine | Asendin |
| Clomipramine | Anafranil |
| Desipramine | Norpramin, Pertoframe |
| Doxepin | Sinnequan, Adapin |
| Imipramine | Tofranil |
| Maprotiline | Ludiomil |
| Nortriptyline | Pamelor, Aventyl |
| Trazadone | Vivactil |
| Trimipramine | Surmontil |

**MAOI s ( Monoamine Oxidase Inhibitors)**

| | |
|---|---|
| Isocarboxazid | Marplan |
| Phenelzine | Nardil |
| Tranylcypromine | Parnate |

## For Depression, Bipolar Disorders, Obesssive-Compulsive Disorder, Phobias, Panic Disorders, Bulemia Nervosa, Cocaine Abuse, Chronic Pain *(continued)*

**SSRIs (Selective Serotonin Reuptake Inhibitors)**

Citalopram . . . . . .Celexa
Escitalopram . . . . . .Lexapro
Fluoxetine . . . . . .Prozac
Paroxetine . . . . . .Paxil
Sertraline . . . . . .Zoloft

**SARIs (Serotonin Antagonist Reuptake Inhibitors)**

Nefazodone . . . . . .Serzone

**Atypical Antidepressants**

Bubropion . . . . . .Wellbutrin
Mirtazapine . . . . . .Remeron

**SNRIs (Serotonin and Norepinephrine Reuptake Inhibitors)**

Venlafazine . . . . . .Effexor

## Bipolar Disorders

**Generic Name . . . . . .Brand Name**
Carbamazepine . . . . . .Tegretol
Divalproex . . . . . .Depakote
Lamotrigine . . . . . .Lamictal
Topiramate . . . . . .Toparmax
Valproic Acid . . . . . .Deprakene

## Anxiety Disorders

**Generic Name . . . . . .Benzodiazepines Brand Name**
Alprazolam . . . . . .Xanax
Diazepam . . . . . .Valium
Chlordiazepoxide . . . . . .Librium
Clonazepam . . . . . .Klonopin
Clorazepate . . . . . .Tranxene
Flurazepam . . . . . .Dalmane
Lorazepam . . . . . .Ativan
Triazolam . . . . . .Halcion
Zaleplon (Non-benzodiazepine) . . . . . .Sonata
Zolpidern (Non-benzodiazepine) . . . . . .Ambien

## Appendix B: Suggested Pre/Post Questions

1. The goal of the Louisiana C-PASS Program is to provide community-based assistance services to individuals with psychiatric disabilities.
   - ☐ a. True
   - ☐ b. False

2 The individual receiving services will not only decide what services they receive, but who will provide the services and in what manner those services are provided.
   - ☐ a. True
   - ☐ b. False

3. Most people with serious and persistent mental illness are incurable, permanently disabled, and still live in institutions.
   - ☐ a. True
   - ☐ b. False

4. The inspiration for the provision of personal assistance to persons with psychiatric disabilities comes from the civil rights movement in the 1950s.
   - ☐ a. True
   - ☐ b. False

5. Personal assistance work is built on the following beliefs that the person who hires a helper has: 1) the right to fail, 2) the right to be as independent as possible, and 3) the right to make his or her own choices.
   - ☐ a. True
   - ☐ b. False

6. A PAS provider is someone who is a professional with an academic degree.
   - ☐ a. True
   - ☐ b. False

7. PAS services are just like the traditional mental health services but done at home.
   - ☐ a. True
   - ☐ b. False

8. Mental illness can affect persons of any age, race, religion, or income.
   - ☐ a. True
   - ☐ b. False

9. Recovery from mental illness happens quickly and causes very little problems if the person tries very hard to get better.
   - ☐ a. True
   - ☐ b. False

10. Keeping information confidential is very important for the PAS worker.
   - ☐ a. True
   - ☐ b. False

## Answer Key for Pre/Post Questions

1. T
2. T
3. F
4. T
5. T
6. F
7. F
8. T
9. F
10. T