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Independent Living: Its Principles and Practices

History and Philosophy of the Independent Living Movement

The Independent Living (IL) movement has its origin in the late sixties and early seventies when our society was in the midst of the growing civil rights movement.

Ed Roberts, who is considered one of the founders of the IL movement, enrolled in the University of California at Berkeley but was denied admission due to his disability. He challenged that decision and won the right to attend the university, but was forced to live in the infirmary. Revolting against the restrictions and the image of being sick, Ed and a few other students organized practical supports such as accessible housing, personal assistant services and moved out. Hearing of their success, many contacted them for information and support. In response to these requests, the first Center for Independent Living (CIL) was formed. A CIL is a non-residential, not-for-profit, community-based agency providing the core services of Independent Living.

A CIL is more than just an organization - it embodies a movement with a philosophy rooted in principles similar to the civil rights and women’s movements. The Independent Living movement developed in response to systems that were inappropriate for people with disabilities.

The philosophy of disability rights and independent living hold to principles, that contrast the IL model or paradigm with the traditional rehabilitation paradigm. In the IL model, the society with its barriers and negative attitudes toward disability is the problem in need of change, rather than the individual with a disability.

The IL movement has fostered a particular definition of Independence. "Independence is the ability to control one's own life by making responsible choices from acceptable options."

To help ensure some "acceptable options" and to prevent inappropriate institutionalization, CILs offer a variety of services. There are four core services that every CIL must offer. These are: Advocacy, Independent Living Skills Training, Information and Referral, and Peer Counseling. In addition, there are many other services that a CIL may provide. The specific services a particular CIL offers is determined by a number of factors including available funding and resources, as well as, the expressed needs of the local community.

As of August 2002 there are 24 centers in Illinois. Established in October 1988, Progress Center for Independent Living (PCIL) serves all of suburban Cook County.

Progress Center Programs:

Advocacy

Knowledge of legislation that ensures equal access and protects against discrimination, is a vital part of an independent and empowered life. Progress Center staff educates people with disabilities about their rights and how to be effective self-advocates. PCIL staff also works with
other individuals and agencies to promote systemic change in policies and practices that may discriminate against people with disabilities.

**Independent Living Skills Training**

Center staff work with consumers with a variety of disabilities to assist them in learning the skills necessary to assume responsibility for the direction of their lives and to participate more fully in their communities. Information can be shared one-on-one or in a group setting on topics such as budgeting, home management, job seeking skills, how to become an effective manager of personal assistant services or in accessing and using public transportation.

**Information and Referral**

Individuals who have questions on disability related topics can contact PCIL and we will look through our resource materials to answer these questions, or refer them to another appropriate agency. Frequently asked questions range from locating accessible and affordable housing, transportation options, accessing Personal Assistant Services, and adaptive equipment, among other subjects.

**Peer Counseling**

A hallmark of the Independent Living movement is the recognition of the benefit of people with first-hand knowledge of disability sharing their experiences and insights with those who seek to enhance their independence. Staff and volunteers can serve as peer mentors and offer support, as consumers set goals and work toward improving the quality of their lives.

**TTY Distribution**

Under a contract with the Illinois Telecommunications Access Corporation (ITAC), Progress Center serves as a regional site to distribute TTY’s to people who are deaf, hard of hearing, or have speech disabilities. PCIL staff also provides training on proper TTY use.

**Transportation and Travel Training**

Progress Center has a contract with the Regional Transportation Authority (RTA) to teach consumers with a variety of disabilities how to use the mainline public transit system. Also the team is involved in the process of determining eligibility for Paratransit, or door-to-door service. This program serves residents of Suburban Cook, DuPage and Lake Counties. A member of the travel training team attends PACE meetings and serves on the CTA and RTA advisory committees.

**Personal Assistant Recruitment and Referral**

Progress Center's personal assistance team provides information on how to access needed personal assistance services. A personal assistant (PA) is someone hired by an individual with functional limitations to assist them with activities of daily living they would perform for themselves if they did not have a disability. This may include bathing, dressing, cooking,
cleaning, shopping and laundry, among other tasks. Progress Center's personal assistance team recruits individuals interested in working as PAs, providing orientations to them and referring them to prospective employers. We can also provide information to people with disabilities and their families in order to identify other available community resources. In addition, the PA team and their colleagues engage in advocacy to improve the quality and availability of community-based personal assistant services and works to prevent inappropriate institutionalization.

Community Reintegration Project

In March of 1998, Progress Center applied for, and received, a grant from DHS/ORS Home Services Program; to assist people in nursing homes and other long term care facilities, to transition back into the community. This program provides funding for individuals in institutions to pay for rent and utility deposits, and to purchase needed household items.

For more information on Independent Living, or other Progress Center services available, please feel free to contact us at: 708-209-1500 (VOICE) or 708-209-1826 (TTY).
Assessing Your Own Needs

Making a needs assessment is the first step when recruiting a Personal Assistant (PA). If you are not sure of all the needs you have, how can you possibly list them for someone else? Once you do this, it is then possible to create a schedule and contract. Aside from physical needs, you will want to consider your likes and dislikes. Some possibilities to consider are:

**Lifestyles**

A. **Drugs**
   If the use of drugs or alcohol is an issue with you or potential Personal Assistants, this matter should be discussed in depth during the interview. Attempt to clarify if, when, where, and how much alcohol and drug use is acceptable to both you and the potential PA.

B. **Sex**
   Few topics are as traditionally difficult to discuss as sex. If, however, the PA is going to be a live-in, as the employer you may want to discuss whether overnight guests are permitted. Also, indicate that you may occasionally have an overnight guest. It is important that you recognize and explore your feelings on the subject of sex and be open to discussing them with the prospective PA.

C. **Smoking**
   Many people have respiratory problems or may be allergic to smoke. If cigarette smoke bothers you or a member of your household, guidelines for smoking need to be set during the interview.

D. **Meals**
   If part of the Personal Assistant’s duties includes the preparation of meals, you need to discuss preferences regarding the type of food and manner of preparation, special diets and any possible limits on use of the kitchen. If you will be sharing food with a live-in PA, you need to discuss the issue of cost sharing.

E. **Cleanliness**
   While attendant care is often restricted to personal/physical care, household cleanliness should also be discussed. Some of the PA’s duties may include cleaning the home if needed, and is agreed to during the development of the contract. Be specific regarding the degree of cleanliness expected, including how often dusting, sweeping, mopping, and other duties must be completed.

F. **Emergencies/Coverage for days off**
   Inform PAs about what to do in an emergency. You are responsible for defining emergency conditions and identifying people to notify during an emergency. Guidelines must be set up for notifying you in case your PA has an emergency and is unable to work. Arrangements for emergency coverage should be made prior to an emergency occurring. One resource that you may want to use is a home health agency. Since these services usually require an intake
interview and assessment, you should assure that these steps are taken prior to the need for emergency services.

G. Sleep schedule
If the PA will be assisting you in getting in or out of bed, a schedule will need to be developed identifying the times that this assistance is needed. As with all duties, the development of a PA's schedule is your responsibility initially and must be adhered to by both parties unless there is prior agreement to adjust the schedule. Do not forget to include the schedule for turning in bed during the night, if necessary.

H. Other areas of concern
Try to mention as many other activities as possible prior to the hiring. These activities may include telephone messages, meals for guests, use of motor vehicles, participation in religious holidays, the temperature of the house, use of the television and stereo, etc.

The following pages include a sample of a needs assessment. After you have filled it out, (including your own list of likes and dislikes) you will be ready to start the hiring process.

Needs Assessment Sample

The first step in using attendant services is to decide what activities you need help with. This checklist gives you a general outline of what duties a PA might perform. Go through the list, and place a check next to each activity where you need assistance. It is also helpful to write how long it takes for each activity. Note the blank spaces labeled "Other". This is for any activities that are not already included on the list. Write those additional activities in the spaces.

1. Bathing ______________________
2. Dressing ______________________
3. Housekeeping ______________________
   a. Daily ______________________
   b. Weekly ______________________
   c. Monthly ______________________
4. Medications ______________________
5. Range of Motion Exercises ______________________
6. Eating ______________________
   a. Shopping ______________________
   b. Meal preparation ______________________
c. Clean up ______________________

7. Bathroom Assistance ______________________
   a. Bowel Program ______________________
   b. Bladder Program ______________________
   c. Other: ______________________
      i. ______________________
      ii. ______________________

8. Transfers ______________________
   a. Bed to Wheelchair ______________________
   b. Hoyer Lift ______________________
   c. Sliding Board ______________________
   d. Other: ______________________
      i. ______________________
      ii. ______________________
      iii. ______________________
      iv. ______________________

9. Miscellaneous ______________________
   a. Recreation ______________________
   b. Errands ______________________

10. Other: ______________________
    a. ______________________
    b. ______________________
    c. ______________________
    d. ______________________
    e. ______________________
f. ____________________
g. ____________________
h. ____________________
i. ____________________
The Hiring Process

Advertising/recruiting methods

1. Progress Center for Independent Living
   Since you live in the area, you can request a list of our potential Personal Assistants. Progress Center provides a brief orientation to the PAs we recruit, however, it is up to you to screen and train the PAs you hire. If you have any other questions contact the Personal Assistance Team. Our mission is to help you become a more effective employer.

2. Classified Ads
   Many persons with disabilities feel that placing classified ads is the best way to recruit potential PAs. The first step is to contact your local newspapers and compare prices. For how long and when you run the ad is up to you. Keep in mind that some newspapers have discounts for ads running longer and on particular days. It is a good idea to contact papers that are free to the public. Your ad will be seen by more people this way. College papers and church newsletters are also a good place to try.

   The kind of response you get from your ad will depend on how the ad is written. Although the newspaper will often write the ad for you, it is usually better to do it yourself. Include the name of the position, a brief description of the duties, and telephone numbers where you can be reached. Do not include your name and address in the ad to avoid having people show up to check on the job. It is also helpful to give applicants an idea of the hours required and list any needed experience and qualifications (i.e. personal care). This will eliminate unsuitable applicants. Be clear, concise, and remember ads usually charge by the number of spaces you use, so you don't have to use perfect English. Also, do emphasize job benefits. An excellent way to attract applicants is to include a bold heading describing a job benefit.

   Below are several examples of classified ads:

   ASSISTANT TO DISABLED FEMALE - duties include personal care driving housekeeping 6hr/day $5.56/hr 555-555-7637
   EXCELLENT FOR STUDENT - Room and board flexible hours assist disabled male with daily activities Call 555-555-2341
   TIRED OF MINIMUM WAGE? Wanted to assist disabled woman with personal care and housekeeping 5.50/hr - 8a-4pm. For info call 555-765-8765

3. Work-wanted Ads
   Check the ads placed by people looking for jobs. Who knows, there may be a potential PA among them. If people have made the effort to place an ad, at least you know they are willing to work.

4. Bulletin Boards
   Posting bulletin board ads is a great, free way to recruit PAs and can be found throughout the community. Churches, colleges, libraries, grocery stores, and hospitals usually all have
bulletin boards.

Be sure you choose the words for the bulletin board ad carefully. Also, make sure it is placed at eye level, so it is easier for people to see. Check to see that the lettering is visible from a distance. Having small sections with your number on each that can be torn off makes it easier for getting your message out.

Be sure to check to see if your community offers an ad posting service. When posting ads, observe any rules for using a bulletin board, and check your ads often to make sure they have not been covered or thrown away.

5. **Family and Friends**
   If you are a participant in the Illinois Department of Human Services/Office of Rehabilitation Services/Home Service Program (ORS/HSP), certain family members may not work as your personal assistants. Using family and friends as PAs can be a problem at times because it is very difficult to maintain your relationship and supervise them. However, it is a good idea to ask family and friends for referrals of others you might hire.

6. **Employment Service**
   List your job opportunity with local employment services. Many people who are out of work check there for available jobs. A good resource is the Illinois Department of Employment Securities at (312) 793-5700.

**Screening Applicants**

All applicants, whether they have responded to your classified ad or have been referred by friends, family, or PCIL, should be thoroughly screened before you hire them. The first screening step occurs when an applicant calls to inquire about the job. Here are some suggestions for conducting a telephone interview:

1. Answer the phone in a friendly manner.
2. Give a brief description of duties, hours, and pay.
3. Be sure to mention that the job includes some nudity and bowel and bladder care, if it does.
4. If the person sounds interested, ask them a few basic questions:
   a. Name?
   b. Address?
   c. Do you have your own phone? What is the phone number?
   d. Have you had any relevant experience?
   e. Why do you think you would be interested in the job?
f. Level of education?

g. Do you have reliable transportation?

5. Tell them you will call them back to schedule a personal interview when you are ready and thank them for calling.

Even if the person does not seem suitable for the job, always thank them for their interest. You may want to file their name and address; it may come in handy in the future.

**Here is how Sue screened a potential PA (Pat) over the phone:**

The telephone rings.

**Sue:** Hello

**Pat:** Hi. This is Pat Smith. I saw your ad in the paper, and I am interested in the job.

**Sue:** Oh, that's great. Can you speak up a bit? It's hard for me to hear you.

**Pat:** Sure, is that better?

**Sue:** Yes. Do you know anything about Personal Assistance work?

**Pat:** Well kind of. I have a friend who uses a wheelchair, and I've helped her several times when her regular PA couldn't come.

**Sue:** Well, this position is pretty regular. I need someone for 6 hours a day, 2 hours in the morning and 4 hours in the evening. If I can get someone to work for 6 hours, I'd prefer to hire just one person. But some people prefer fewer hours, especially on weekends. I may need to hire two people. What is your schedule?

**Pat:** Well, I can work either days or evenings, but I'm not sure about both. I don't mind switching from one week to the next, though and I'd like to work every other weekend.

**Sue:** Well, that's a possibility. Let me tell you about what I need. My personal assistant needs to get me up in the morning, bathe me, dress me, and fix me breakfast. This routine involves bowel and bladder care, so you have to be comfortable with that.

**Pat:** Yes, I see.

**Sue:** In order to do my work I also need my computer set up because I do volunteer work for our local CIL.

**Pat:** O.K. And the evening?

**Sue:** Well, I need my work put away, dinner made, served, and clean up afterwards, and I need to be undressed and helped to bed. I also need cleaning and shopping done on a weekly basis. There are more specifics, but that's the general idea. Are you interested?
Pat: Yes, I am. I may be willing to work both shifts, but I'd like to meet you and talk about the details first.

Sue: That sounds good to me. Give me your name, address, and phone number, slowly. I can't write, so I have to put it on my computer. Then we'll schedule an interview.

Pat: O.K. It's Pat Smith, 123 Tree St., 123-456-7890

Sue: Would you tell me again about any experience you have?

Pat: Oh, yes. I have been an attendant for Pamela L. several times, and I have also worked as an aide in a nursing home one summer.

Sue: Yes and can you tell me about your education, and most important, whether you have reliable transportation?

Pat: Well, I'm a sophomore at the University, and my classes are all in the afternoon. I do not have a car, but I have a bike, and I take the bus. Are you on the bus line?

Sue: Yes, I'm only a block from the stop on Fourth Street. But it's hilly here, and your bike might not make it in bad weather. Are you willing to take the bus often if you have to? Sometimes it takes a while.

Pat: Oh, yes. I sometimes do my homework on the bus, and I am used to it.

Sue: I'd like to interview you. Can you meet me at Progress Center for Independent Living at 10 a.m.?

Pat: Yes, that sounds fine.

Sue: O.K. I will see you then.

Interviewing

The next task is to go over the information on each applicant, and select those most qualified. These applicants can then be invited to a personal interview, one at a time. If possible, schedule as many qualified applicants for personal interviews as you can.

When inviting applicants for a personal interview, you may prefer to meet with them in a neutral place rather than giving them your address. Some PA employers prefer to meet in their homes in order to give the applicant the opportunity to try certain tasks. Ask them to bring the names and addresses of at least 2 personal and/or work references, driver's license, and Social Security card.

Often applicants will not show up for the interview. This may be frustrating, but at least you know you won't have to rely on an irresponsible person for assistance.
Here are some suggestions for a personal interview and a sample interview:

1. Greet the applicant in a friendly manner.

2. Get acquainted, make small talk, and describe your disability.

3. Give the applicant the checklists to look over to describe specific duties.

4. Inform the applicant of the hours he/she will be required to work, rate of pay, and the pay schedule.

5. Explain any procedures for absenteeism and tardiness. Tell the applicant that you will explain any reason for termination if this should become necessary.

6. Ask the applicant to fill out an application including at least 2 references.

7. Review the application, making sure it is filled out correctly.

8. Tell the applicant that you will call as soon as you make a decision.

9. Thank them for their time.

Sample Personal Interview

Sam: Hi, I'm Sam Smith. Why don't you sit down?

Ann: Thank you.

Sam: Did you find your way all right?

Ann: Yes, fine.

Sam: Good. Why don't we get started then? We talked a little on the phone about your experience. Could you tell me more?

Ann: I used to volunteer in a nursing home for about a year.

Sam: What kinds of things did you do?

Ann: I would get things for the residents and play cards. Things like that.

Sam: Well, this job is a lot different. My disability is a spinal cord injury, which means that I have limited use of all four limbs. The types of things I need help with are dressing, bathing, cooking, cleaning, and shopping. Actually, I have some lists here that describe what I need help with in greater detail. They are on the corner of the table. I'd like you to take a couple of minutes to read them. (Applicant reads the lists)

Sam: Well, do you have any questions?
Ann: This section on catheter irrigation. What does it mean?

Sam: Just as I have difficulty controlling my arms and legs, I have very little control over my bladder so I have a catheter. A catheter is a tube that goes through my stomach right into my bladder. When my bladder gets full, the urine goes out the hose and into a bag that is strapped to my leg.

Ann: Oh, I see.

Sam: I know it sounds complicated, but if you are hired, I will train you how to do it. Do you have any other questions?

Ann: No, I don't think so.

Sam: O.K. Now I just need you to fill out this application.

Sam: (After reviewing application) You forgot to list the address of your last employer. Do you know it?

Ann: I know the street, but I don't know the exact address.

Sam: If you could just write in the street then. (After she writes in info.) Well, everything looks in order. I have a few more people to interview before I make a decision. I have your number, and I'll let you know by Friday. Thanks for coming. It was nice meeting you.

Application

As previously mentioned, it is a good idea to have the potential PA fill out an application. This will provide you with important information and can serve as a guideline for any questions you may have. Even if you do not hire a particular PA, it is helpful to keep their application. They might be a potential back-up PA. Here is a sample of an application:
# Personal Assistant Application

<table>
<thead>
<tr>
<th>Date:</th>
<th></th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Name:</th>
<th>S.S.#</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Address:</th>
<th>City:</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Phone:</th>
<th>Alt. Phone:</th>
</tr>
</thead>
</table>

## Transportation:

<table>
<thead>
<tr>
<th>Days Available:</th>
<th>M( )</th>
<th>T( )</th>
<th>W( )</th>
<th>Th( )</th>
<th>F( )</th>
<th>Sat( )</th>
<th>Sun( )</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Times Available:</th>
<th>AM( )</th>
<th>PM( )</th>
<th>Overnight: Yes( ) No( )</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Emergency Backup</th>
<th>Yes( ) No( )</th>
</tr>
</thead>
</table>

## Comments:

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### Employment Experience

<table>
<thead>
<tr>
<th>Employer:</th>
<th>Phone:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Address:</td>
<td>Supervisor:</td>
</tr>
<tr>
<td>Position:</td>
<td>Date Employed: From: To:</td>
</tr>
<tr>
<td>Reason for Leaving:</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Employer:</th>
<th>Phone:</th>
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</tr>
<tr>
<td>Position:</td>
<td>Date Employed: From: To:</td>
</tr>
<tr>
<td>Reason for Leaving:</td>
<td></td>
</tr>
</tbody>
</table>

**Applicant’s Statement**
I certify that all information provided is true to the best of my knowledge.

(Signature of Applicant) (Date)
## Reference Check Form

<table>
<thead>
<tr>
<th>Employer:</th>
<th>Phone:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Address:</td>
<td></td>
</tr>
<tr>
<td>Position:</td>
<td>Supervisor:</td>
</tr>
<tr>
<td>Date Employed:</td>
<td>From:</td>
</tr>
<tr>
<td>Reason for Leaving:</td>
<td></td>
</tr>
</tbody>
</table>

What would you say are the applicants strength?

What would you say are the applicant's weaknesses?

How would you compare applicant's work to the work of others who have had the same job?

How dependable was applicant when working for you?

Was applicant honest?

Did applicant complain very much about anything?

How did applicant let you know when there was something he or she didn't like or agree with?

How often was applicant late for work?

How often did applicant miss work?

What kind of driver was applicant (if appropriate to former job)?

Would you re-hire applicant?
**Checking References**

It is very important to check the references of every potential PA. It is always best that they provide you with work references. After all, it is unlikely that a personal reference will give you any reason not to hire the person. Here are some sample questions to ask the former employer:

- When did the applicant work for you?
- Would you re-hire the applicant?

Many companies have taken the stance of answering very little about a former employee for legal reasons. If you encounter this response when checking references, the 2 questions above are usually allowed. Though they are not in depth, if the employer states they would not re-hire the person that will give you an idea that something is not right. Also, if the person did not work there for a very long time, it can give you an idea of how long the person sticks with a job. While checking references, ask yourself “Does the person have a habit of jumping from job to job”? If you are seeking a PA for long-term work, this is probably not a good candidate.

**Making A Decision**

Hopefully, you will now have several qualified applicants from which to choose. This decision is made totally by you, the employer; so take some time to review each application. Some suggestions to help you make your decision are provided below:

1. **Decide what kind of attendant you want.** Then look at each candidate, and see how he or she meets each of your expectations. Sometimes you don't have a wide range of choices. You may have less-than-perfect candidates.
   - a. What minimum requirements are to willing to settle for?
   - b. Do you want to hire someone immediately, but continue to search for a better long-term attendant?
   - c. Or, can you wait until the right attendant comes along? These are all issues you need to consider carefully.

2. **Check all the applicants' references.** The best indicator of an applicant's work performance is his/her work history. Be cautious if the person has not worked before or does not list work-related references. The applicant may have listed many personal references, but these people probably know very little about the applicant's work performance.

3. **Other important factors might include:**
   - a. Does the applicant have a phone?
   - b. Reliable transportation?
c. Job experience related to attendant care?

**Hiring An Applicant**

You have made your decision and are ready to hire your new personal assistant. It is now time to call that person and arrange their first workday.

Be sure you also call the other applicants and tell them you have hired someone else. You may wish to ask qualified applicants if they would be interested in working as an emergency back up. It is a good idea to keep their application on file, because it may save you time in the future.

**Making A Contract**

So that each of you has a clear idea of duties and responsibilities, you will need to develop an employment contract. The important thing is to ensure that all aspects of your working and social relations (for live-in attendants) are covered. The following pages are sample contracts. Please take time to change them to reflect your own needs.

**Employment Contract**

**Employment Contract Between:**

( Employer Name )  ( Personal Assistant Name )

**Work Schedule:** (Circle the appropriate days)

<table>
<thead>
<tr>
<th>Mon</th>
<th>Tue</th>
<th>Wed</th>
<th>Thur</th>
<th>Fri</th>
<th>Sat</th>
<th>Sun</th>
</tr>
</thead>
</table>

**Hours to be worked:**

From:  To:

From:  To:

**Salary:**

<table>
<thead>
<tr>
<th>Per Hour</th>
<th>Per Week</th>
<th>Per Month</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cash</td>
<td>Check</td>
<td>Withhold Tax: (Yes or No)</td>
</tr>
</tbody>
</table>

**Benefits Provided for PA:**

<table>
<thead>
<tr>
<th>Room:</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Meals:</td>
<td>Yes</td>
<td>No</td>
</tr>
</tbody>
</table>
Laundry (for live-in PA): Yes No

Utilities included (for live-in PA): Yes No

Utilities the PA must pay for:

Use of Personal Property items: (i.e. vehicle only as employer wants used):

______________________________________________________________________________
______________________________________________________________________________

Acceptable Social Behavior:

Swearing: Yes No
Smoking: Yes No
Drugs: Yes No
Drinking: Yes No
Overnight Guests: Yes No

Employer’s Responsibilities:
- Employer will not expect PA to stay past the agreed upon time (Except in emergency situations).
- Employer will be ready to work promptly upon the PA’s arrival.
- Employer will maintain records on PA’s performance.
- Employer will respect the personal assistant.

Personal Assistant’s Responsibilities:
- Personal Assistant will be on time.
- Personal Assistant will perform all duties as outlined by employer.
- Personal Assistant will complete the duties by the agreed-upon time.
- Personal Assistant will respect the confidentiality of the employer.
- Personal Assistant will respect the employer’s personal items.
- Personal Assistant will respect the employer.

Absences:
Both the employer and personal assistant must give at least ____ days advance notice of an interruption to the schedule. In case of an emergency, the employer and the personal assistant must notify each other as soon as possible.

**Termination:**

_____ number of days absent will result in termination.

_____ number of days tardy will result in termination.

Personal Assistant will be reminded _____ times of unacceptable behavior before being terminated. If the PA’s behavior is endangering the employer’s health or safety, the PA will be terminated without notice.

**Termination Notice:**

Each party shall give _____ weeks notice before termination except under extreme circumstances as mentioned above.

I, _______________________________ have agreed to work under the employ of, ________________________________ as a personal assistant.

Duties under this contract will consist of the following:

<table>
<thead>
<tr>
<th>Personal Care</th>
<th>Housekeeping</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bathing</td>
<td>Cooking</td>
</tr>
<tr>
<td>Washing Hair</td>
<td>Vacuuming</td>
</tr>
<tr>
<td>Dressing</td>
<td>Sweeping</td>
</tr>
<tr>
<td>Bladder Care</td>
<td>Mopping Floors</td>
</tr>
<tr>
<td>Brushing Teeth</td>
<td>Cleaning Bathroom</td>
</tr>
<tr>
<td>Grooming</td>
<td>Cleaning Kitchen</td>
</tr>
<tr>
<td>Transferring</td>
<td>Washing Dishes</td>
</tr>
<tr>
<td>Re-positioning</td>
<td>Dusting</td>
</tr>
<tr>
<td>Range of motion</td>
<td>Polishing Furniture</td>
</tr>
<tr>
<td>Skin Care</td>
<td>Shopping</td>
</tr>
<tr>
<td>Equipment Cleaning / Maintenance</td>
<td>Laundry</td>
</tr>
<tr>
<td>(includes wheelchair, commode, bed)</td>
<td>(includes ironing)</td>
</tr>
<tr>
<td>Assistance with Oxygen use</td>
<td>Watering Plants</td>
</tr>
<tr>
<td></td>
<td>Daily Trash Removal</td>
</tr>
<tr>
<td></td>
<td>Driving</td>
</tr>
</tbody>
</table>

My employment will be for a maximum of ___________ approved hours per week. Hours to be worked will be __________ and I have agreed to work __________ days per week for $__________ per hour. I have received and fully understand the list of guidelines and will follow them to the best of my ability. I further understand that any or all terms of this contract may be subject to renewal or change upon agreement.
Emergency Attendants

No matter how dependable your PA is, there will be times when he/she will have to miss work. You can prepare for this ahead of time by developing an emergency back-up system. Keep names and phone numbers of people you can call to fill in for your PA. Back-up PA's may be former attendants, applicants (who were not hired but seem qualified), family members, and friends. You may have these people come in one or two days to familiarize them with your routine. Progress Center can also refer to you personal assistants who have indicated they are willing to work on an emergency basis. You can also call private pay agencies. However, their services are likely to be expensive. Another alternative might be to see if your PA’s (if you hire more than one) will trade shifts for a specific occasion. The important thing is to plan ahead for emergencies.
Training

Before You Begin Training

Time Management/ Developing a Schedule

It takes approximately an hour to prepare for work in the morning for most able-bodied people. Often they are unaware of the time and effort involved to complete individual tasks such as getting out of bed, dressing, brushing teeth, and combing hair for people with disabilities. In order for a PA to know exactly how much time it takes to complete the required tasks, you must personally assess your needs and estimate the time required to complete the task with the assistance of a PA. For your benefit, we have included a sample schedule (following). Notice that daily duties are outlined in fifteen-minute intervals. While you may not want to use this particular schedule, having a schedule of some type is extremely important.

Many PA/employer relationships fail because of inaccurate scheduling. Before interviewing prospective PA’s, monitor how much time it takes to complete each task. Using this information, work up a schedule sheet and review it with the prospective PAs to see whether this matches their free hours.

You should also carefully review personal commitments that must be taken into consideration in the scheduling process.

The following pages are sample schedule sheets. We have included blank schedule sheets at the end of the Manual as well so that you can create your own.
## Personal Care Activities

<table>
<thead>
<tr>
<th>Who will do?</th>
<th>How long does it take?</th>
<th>Daily (D) or day of week to be performed</th>
</tr>
</thead>
<tbody>
<tr>
<td>S=Self</td>
<td>When: M A E N</td>
<td></td>
</tr>
<tr>
<td>F=Family</td>
<td></td>
<td></td>
</tr>
<tr>
<td>PA=PA</td>
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<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Brushing Teeth</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Shaving</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Make-Up</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Dressing</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Transfer:</strong></td>
<td>Bed</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Wheelchair</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Tub/Shower</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Turning in Bed</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Medication</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Eating</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Exercise</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Bathing</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Bowel Program</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Bladder Program</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Undressing</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Preparation for sleep</strong></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### Other Activities

<table>
<thead>
<tr>
<th>Who will do?</th>
<th>How long does it take?</th>
<th>Daily (D) or day of week to be performed</th>
</tr>
</thead>
<tbody>
<tr>
<td>S=Self</td>
<td>Morning</td>
<td></td>
</tr>
<tr>
<td>F=Family</td>
<td>Afternoon</td>
<td></td>
</tr>
<tr>
<td>PA=PA</td>
<td>Evening</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Night</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Recreation (Fun!)</th>
<th>M</th>
<th>A</th>
<th>E</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Household Details (Bills, Grocery List, etc.)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Laundry</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Shopping</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Meal Preparation:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Breakfast</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Lunch</td>
<td></td>
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</tr>
<tr>
<td>Dinner</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Meal Clean-Up:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Breakfast</td>
<td></td>
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<tr>
<td>Lunch</td>
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</tr>
<tr>
<td>Dinner</td>
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<td></td>
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</tr>
<tr>
<td>Cleaning:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bedroom</td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Bathroom</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Kitchen</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Floors</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dusting</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mopping</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>School, Job, Etc.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Driving / Mobility</td>
<td></td>
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</tr>
<tr>
<td></td>
<td>Monday</td>
<td>Tuesday</td>
<td>Wednesday</td>
<td>Thursday</td>
</tr>
<tr>
<td>-------</td>
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<td>------------------------</td>
<td>-------------------------</td>
<td>------------------------</td>
</tr>
<tr>
<td><strong>Morning</strong></td>
<td>Up 8:00</td>
<td>Bath</td>
<td>Up 7:00</td>
<td>Up 8:00</td>
</tr>
<tr>
<td></td>
<td>Breakfast 9:30</td>
<td></td>
<td>Dust and vacuum</td>
<td>Breakfast 9:30</td>
</tr>
<tr>
<td></td>
<td>Up 8:00</td>
<td>Bath</td>
<td>Up 7:00</td>
<td>Up 8:00</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Lunch 12:30</td>
<td></td>
</tr>
<tr>
<td><strong>Afternoon</strong></td>
<td></td>
<td></td>
<td>Water Plants</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Wash kitchen floor</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Evening</strong></td>
<td>Diner 6:00</td>
<td></td>
<td></td>
<td>Diner 5:00</td>
</tr>
<tr>
<td></td>
<td>Fix snacks for football game on TV</td>
<td>Library 7:00</td>
<td></td>
<td>Choir Practice 7:00</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>9:00</td>
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<tr>
<td>Monday</td>
<td>Tuesday</td>
<td>Wednesday</td>
<td>Thursday</td>
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</tr>
<tr>
<td>Morning</td>
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<tr>
<td>Afternoon</td>
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</tr>
<tr>
<td>Evening</td>
<td></td>
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</tr>
</tbody>
</table>
Explaining Pertinent Medical Information

The best person to teach the PA about your disability is you. It is very important that you inform your PA about your specific medical needs. This is especially important if the PA will be assisting you with dispensing medication or preparing meals. For example, if your PA will be cooking meals for you, are there certain foods you cannot eat? The following worksheet is provided to help you educate your PA.

1. The medical term for my disability is: ____________________________

2. Some ways in which the disability affects me are: ____________________________

3. I take the following medications: ____________________________

4. You should know the following about the medication I take: __________________

5. Foods I should not eat are: ____________________________

6. In case of an emergency, you should contact: ____________________________

It is also a good idea for your PA to provide you with any medical information you should be aware of. The PA also should give you names and phone numbers of people you should contact in case something happened to them. This is important to have because accidents happen every day, even to the healthiest people.

Using The Checklists To Train PA’s

Before you train your new PA, you need to decide how flexible you want to be and if you prefer a socially oriented situation or more of a professional relationship. How you train your PA will influence how you interact together.

For example, Susan trained her PA quickly so they could get the basics done and concentrate on details as they got to know each other. On the other hand, Bob preferred to train his PA step by step to make sure everything was done properly from the beginning. Susan and her PA took longer to work out their routine, but they are happy with the arrangement, and they share a close personal relationship. Bob is also pleased with his situation, and his PA likes knowing exactly what he has to do and when.

Once you have decided on what personal training style you prefer, make sure that your PA understands each item on the checklist. Concentrate on one activity at a time. One way to do this is to have the new PA follow along on the checklist while watching your former PA perform the activity. Encourage the new PA to ask questions about any details he or she is unsure of. If a person familiar with your routine is unavailable to serve as a model, you may want to discuss each item on the checklist with the new PA before he/she actually performs the activity.

You are now ready to begin on the job training. Begin by having the PA review the checklist and ask questions about any duties he or she is unsure of. This gives the PA an outline
of the expected outcome. While both you and the PA refer to the checklist, begin the routine one step at a time. Remember, checklists do not provide all the details about how a particular task should be performed. It's your responsibility to give detailed verbal instructions to make sure the PA knows exactly how you want the job done.

One of the purposes of the checklists is to provide the PA with a visual picture of what needs to be done, and in what order. You may want to consider enlarging your checklists and posting them where the PA can see them while they perform their routine. This is especially useful for tasks like house cleaning or shopping, where you cannot always watch and give instructions on the task being performed. Making the posters visible from a distance involves taking them to your local copy center and having them enlarged. We have found the cost for this is minimal. Another possibility is to have a friend handprint the checklist onto a piece of poster board.

You may not want to live in a home decorated with checklists. There are several ways to post the checklists inconspicuously. For example, checklists can be posted on the back of closet and cabinet doors. During the routine, the doors can be opened so the PA can see the checklist. Once the routine has been finished, the doors are closed. If this is not possible, checklists can be attached to poster board and hung on wall hooks while the routine is performed. When you are finished, they can be taken down and stored in a closet or under a bed.

Posting checklists may significantly decrease the amount of time it takes to train your PA. Once your PA has been trained satisfactorily, the posted checklists can be put away until you need to train a new PA or refresh the memory of your current PA.

Using The Checklist To Give Training Feedback

1. Positive Feedback

One of the most important aspects of training your PAs is giving them feedback on how they perform the job. This model focuses on two types of performance feedback during training - positive and corrective. Positive feedback is simply telling the PA what was done well. Research has shown that job performance improves and remains high when employees receive positive feedback on jobs they perform well.

Effective positive feedback has 2 basic parts: praise and specifying exactly what was done well. For example, "My hair feels so clean, you really did a great job washing it today." The easy part of giving effective positive feedback is saying what was done correctly. Praising good work can be more difficult. Praise involves letting another person know you are pleased. This usually consists of using adjectives such as good or great. Be careful not to always use the same adjective when giving positive feedback. If you use "good job" every time, the feedback becomes boring and mechanical, and it may lose its effectiveness. So be creative, and don't be afraid to use lavish praise when your PA performs exceptionally well.

a. Here are some examples of ways to give positive feedback:

i. You really did a great job of...
ii. I really like the way you...

iii. You did such a good job at... it will make my whole day easier.

2. Corrective Feedback

The second type of performance feedback is corrective feedback. Corrective feedback explains exactly why a task was performed incorrectly and gives specific instructions on how to correct the problem. For example, "We need to work on combing my hair. I really prefer my part a little more to the left." Using corrective feedback allows you to correct errors during training in a constructive, non-punishing manner.

When giving your PA corrective feedback, you should be assertive but non-punitive. During training, you are in a position to establish the tone of your future working relationship. Remember, errors made during training are usually due to your PA's unfamiliarity with your personal care routine. If you become angry and yell at your PA, he or she is liable to become frustrated and confused about what you expect. Corrective feedback allows you to be assertive but in a constructive way. First, you explain exactly what was done incorrectly, and then you provide instructions on performing the task correctly next time. Now the PA knows not only what was done wrong, but how to correct the error in the future.

If your PA performs only one part of a task incorrectly, it is a good idea to mention first what was done correctly. For example, "You did a good job on my bath today, but next time please use a little more lotion."

a. Here are some examples of corrective feedback:

i. My hair is still a little wet. Next time let's use the dryer on it a little longer.

ii. When you transfer me in the Hoyer lift, be sure to put the chains facing out, so they don't dig into my side.

iii. These eggs are really good, and I like my bacon a little bit crispier.

3. When to give feedback

For performance feedback to be most effective, it should be given immediately after the PA performs a task correctly or incorrectly. In many cases, feedback can be given during the routine. Another idea is to have a feedback session at the end of each day where you and your PA can sit down and discuss what areas need improvement.

Although occasionally you might hire PAs who are irresponsible or don't care, most applicants want to do a good job. A PA's ultimate job performance depends largely on how well you train him or her. Some final guidelines to follow when using checklists to train new PAs are listed below:

a. Always refer to the checklists and try to follow them closely. If you skip steps on some days, the PA may have trouble anticipating when they are to be performed.
b. Give feedback after every training session. During training, you should review the checklist, and give feedback immediately after each training session.

c. Be positive. This is probably the most important thing to remember when training new PAs.

d. Be specific and constructive. When a step on the checklist is not performed well, explain to the PA specifically what parts of the task need improvement.

Example of incorrect and correct training techniques:

i. SAY - I don't wash my hair on Wednesdays. So let's skip the hair washing today.
DON'T SAY - Let's skip the last few steps today. I don't feel like doing them.

ii. SAY - We will be reviewing the checklists at the end of each day to make sure you really understand what needs to be done.
DON'T SAY - I'll talk to you about it at the end of the week.

iii. SAY - On the hair-combing step, I'd like the part to be more to the left side of my head.
DON'T SAY - You combed my hair wrong.

**Interpersonal Communication**

1. **Asking Questions**
   To make the relationship with the Personal Assistant work effectively, you must convey your needs, identify methods for meeting those needs, and gather information regarding the strengths and deficiencies of the PA. By asking questions, you may avoid learning through trial and error. Your ability to ask questions is the first step toward establishing good communication.

2. **Criticism**
   When working with a PA, you may find it necessary to correct the way he/she performs a task. Be diplomatic in these corrections and be sure to communicate respect. A good rule of thumb is to deal only with the particular task or incident and avoid evaluating the PA's values and lifestyle.

3. **Non-verbal Communication**
   Body language is a term describing the way we move and position our bodies. Body language conveys a message to another person as easily as verbal communication. Be aware of what your body is saying, especially your face. It is also important to have good eye contact when speaking to someone.

4. **Assertiveness**
   Being assertive means doing what is best for you without violating the rights of others. It requires making eye contact, respecting the other individual, and being able to say no without
feeling guilty. Assertiveness can be defined as open, adult communication and is a learned behavior. Practicing assertiveness skills and building a framework of assertive statements is helpful. The following list will aid in this process:

a. Think and talk positively about yourself. The ability to make positive self-statements in conversation helps you to increase your self-respect and confidence.

b. Don’t use the word “but”. Instead use the word “and”. People tend to stop listening to you if you say: “Yes you are generally on time, but it would be better if you called when you are going to be late”. If instead you say: “Yes you are generally on time, and it would be better if you called when you are going to be late”, people will not stop listening, they will feel less defensive.

c. Use 'I' statements. "I" statements show that you take responsibility for what you say. This is especially effective when giving constructive criticism. For example: "I want you to use a different shampoo next time you wash my hair." Instead, of using "It would be nice if you would use a different shampoo."

d. Accepting criticism. When people work together, there may be conflicts. The ability to communicate in a direct, open, and clear manner improves any working relationship. An effective way of dealing with conflict is to listen to the other person's point of view.

e. Speaking to the other person as an adult. It is important that you speak to your PA's as adults and equals. Avoid being parental regardless of the difference in ages and remember, the PA is your employee, not your child.

f. Giving and receiving compliments. If a PA is doing a good job, an assertive "thank you" shows appreciation. A genuine "thank you" gives a clear message that a completed task or thoughtful gesture met or exceeded your expectations.

Remember: Assertive behavior is learned and takes practice and skill.

**Evaluation And Disciplinary Action**

You should, on a regular basis, evaluate your PAs. The most effective supervisors are those who sit down with their worker on a regular basis and provide direct feedback.

Occasionally, despite your best efforts to provide direction and to communicate effectively, a PA will make an error in judgment. This error may be as trivial as a method for preparing a meal or as severe as a theft from the home. One method for dealing with employees who exercise poor judgment is a three-step process of disciplinary action:

**STEP 1:**
**Confrontation** -- Meet face-to-face with the employee and explain exactly what the concerns are, how the problem can be resolved, and what will happen if the error is made a second time.
STEP 2:
**Reprimand** -- The reprimand is a written clarification of the concerns and expectations as well as a description of actions, which will be taken, should the incident occur another time.

STEP 3:
**Dismissal** -- Although dismissing an employee is naturally traumatic, you have already reduced the element of surprise by completing the first 2 steps.

It is important to remember that you are in charge. If you are not happy with the way things are, it is up to you to change it.

**Avoiding Rip-Offs By Attendants**

While there is no way to ensure that you won't be ripped-off by a PA, there are a few common-sense steps you can take to minimize the risk. It is always important to report theft both to Progress Center and the police if necessary or this same PA could continue doing this to other people.

1. Screen PAs thoroughly. This means never hiring someone until you have had an opportunity to check their references. Also, if they have worked for other consumers, it's a good idea to call those consumers to see if they had any problems with the PA.

2. Never leave valuables lying around. The most common items stolen are jewelry and money. Always lock your jewelry in a safe place. It is also a good idea to carry your money on your person. If you use a wheelchair, it should be kept where you can see it.

3. Keep track of your medication. Always keep your medication locked up when you don't need it. Also, keep track of how much you ordered and how much you use. Another tip is to only buy the amount of medication you will need for a two-week period.

4. Avoid letting your PA write checks or withdraw money for you. One of the easiest ways for PAs to steal money is to forge checks. Never give PAs access to your bankcards or checkbook. If you must let them write a check, give them one at a time, and make sure they bring a receipt for the amount of purchase. Pick an accessible bank so you can do your own banking.

5. Never give your credit card to your PA to use. A credit card is one of the simplest ways a PA can rip you off. Your PA can make purchases, sign your name, and be in the next state before your bill comes, and have realized what has happened.

6. Avoid letting your PA use your property for his/her own use. This includes use of your van, phone, apartment, and food. Establishing guidelines of what is allowed and when is a good idea.
7. Be sure to get your key back when a PA quits or is fired. If the PA does not return the keys, have your locks changed immediately. A good prevention method is to have all issued keys stamped with "DO NOT DUPLICATE" on them.
Paying Your Attendant

There are several Federal and State funded programs, which pay for "In Home" Personal Assistance Services in Illinois. For more detailed information on these programs contact Progress Center's PA team.

**Federal and State Programs to Pay PA’s**

**Illinois Department Of Human Services Office Of Rehabilitation Services Home Services Program (ORS/HSP)**

The Home Services Program of the Office of Rehabilitation Services provides funding for qualified individuals, age 59 and under, who would be forced into a nursing home without in-home assistance. Services are managed and supervised by the Consumer and the level of funding is based on the severity of the disability and the availability of other support from friends or family. Funding levels are decided by using the "Determination of Need" (DON) test. The score on the test translates into a dollar amount allowable per month called the "Service Cost Maximum" (SCM). This Service Cost Maximum then determines the number of hours of assistance a Consumer is allowed per day. As of August 2002, Personal Assistants in the ORS/HSP program are paid $7.00/hour. For more information call the Progress Center PA team at (708) 209-1500.

**Illinois Department Of Aging Community Care Program (CCP)**

The Community Care Program serves low-income persons age 60 and over. This program is funded by the Illinois Department of Aging is similar to the ORS/HSP program but with certain differences. The services can only be provided by qualified homemaker agencies that are reimbursed at the agency rate, which means that the maximum amount of services any person can receive is less than the amount of hours available to someone receiving HSP services. Progress Center receives many calls from seniors who tell us they need more help than they are getting to remain in their home. In these cases they can appeal their care plan. For more information call Progress Center's PA team or the Senior Help Line at 1-800-252-8966 for appeals, complaints, and questions or to apply for services.

**Family Assistance/Home Based Support Services Programs**

These programs are funded by the Office of Developmental Disability and the money can be used to purchase home health services, independent living and vocational training, transportation and therapy in addition to Personal Assistance and respite.

The Family Assistance Program provides a monthly cash subsidy to parents of children with severe developmental disabilities or severe emotional problems age 17 and under, whose taxable income is less than $50,000 annually. The monthly amount of assistance is equal to the child's SSI check.
The Home Based Support Services Program serves adults 18 and over with severe Developmental and Mental disabilities and are eligible for SSI or SSDI. Consumers receive up to 3 times the amount of their SSI check in goods and services. Local community agencies assist in identifying needs and arranging services. The service providers bill the State monthly for their services. For more information call 1-800-843-6154, ext. 3, option 1.

To receive applications write to:

Family Assistance/Home Based Support
Illinois Department of Human Services
405 Stratton Building
Springfield, IL 62765

**Paying PA’s Yourself**

You are fortunate if you can pay your own PA. However, it greatly increases your responsibility as an employer. These added responsibilities include:

1. **Minimum wage**
   Personal assistants are considered domestic service workers and are covered by the minimum wage guidelines of federal and state law. Thus, PAs must be paid at least minimum wage.

2. **Social Security tax**
   If you expect to pay your PA $1100 or more in any quarter (3 months), you must pay Social Security tax. The tax rate for 1998 is 7.65% for Social Security and 1.45% for Medicare tax, which you must also pay. The tax rates change annually, so contact your Social Security office for the most recent rates. Complete information on FICA and Federal taxes can be found in Publication 926 from the IRS. It is your responsibility to be current with the information in this publication. For more information call IRS at 1-800-829-3676.

3. **Federal Unemployment tax (FUTA)**
   This tax must be paid if you pay wages of $1000 or more in any calendar quarter. In 1998, your FUTA tax requirement is .008 of gross wage.

4. **Federal Income tax**
   If your PA asks you to withhold income tax you must report the amount withheld. If your PA does not wish for you to withhold income taxes, it is recommended that you ask for this request in writing and keep it with your files.

5. **Illinois State tax**
   Employer responsibilities differ from state to state. You can find what your state does by calling the unemployment or worker's compensation office.

The preceding responsibilities require a substantial amount of paperwork. This will include:

- **a.** Having each new PA you hire fill out a W-4 form reporting the PA's withholding status. Each new PA must have a Social Security #.
b. Filing IRS Form 1040 EZ four times per year listing income tax and FICA withheld, and attaching a check.

c. Once a year, using IRS Form 1040 to pay unemployment taxes for each PA as well as any unpaid income tax and FICA. A Schedule H must be attached for domestic employers.

d. Each year (by 1-31), providing each PA with a W-2 form listing wages paid, FICA taxes withheld, and income taxes withheld.

e. Sending a W-3 form with the W-2 to the Social Security Administration for each PA.

f. Preparing any similar state, city, and county forms for amounts paid to employees.

One way to avoid much of this paperwork is to pay your PA non-cash wages. Non-cash wages include room, food, electric power, and other commodities. In paying non-cash wages, it is important to keep detailed records, receipts, bills, and payment checks. When your PA quits, it is also useful to have him/her sign a statement listing the exact amount of the non-cash wages. It is recommended that you contact your local IRS office to check on non-cash wages policies.

Live-In Attendants

For many persons who are living on limited or fixed incomes, serious consideration must be given to hiring a live-in PA. The first step in this process is determining an "equivalent pay rate." Equivalent pay rate is the formula used to substitute other forms of pay for the PA's salary. For example: an employer is living in an apartment that costs $300 per month and food costs for the employer and the PA are $200 per month. The total room and board costs equal $500. If, for example, the PA is requesting $5.15 per hour for services, the pay would break down as follows:

- One-half of apartment costs: $150.00
- One-half of the food costs: $100.00
- Total: $250.00

$250 per month divided by $5.15 per hour = 48.5 hours

At an hourly rate of $5.15, the employer would be entitled to 48.5 hours of attendant care per month.

Deducting The Cost Of PA Service-Cash Wages

This is not applicable to ORS Home Services participants.

The IRS allows you to take a tax deduction for medical expenses, if they exceed 7.5% of your annual adjusted gross income. In order to claim medical deductions, you must be able to itemize deductions. This requires you to use IRS Form 1040 when figuring your income taxes. To determine if you qualify, simply multiply your adjusted gross income (line 31 on the 1994 Form 1040) by .075 (7.50%). Remember, you can only deduct expenses that were not paid by another source (i.e. insurance, VA). There
is an IRS publication called "Bulletin on Household Help" which explains this issue in detail. For more information call the IRS at 1-800-424-1040.

The key word in taking medical deductions for attendant care is "medical". The IRS has ruled repeatedly that "only nursing-like services" are deductible. You cannot deduct housekeeping duties.

Your checklists can be very helpful when determining how much of your attendant care you may deduct. First, go through the checklists noting each item that is a "nursing-like service." While your routine is being performed, simply keep track of how long it takes to perform only these tasks. This can be done using a stopwatch.

After your routine is over, let's say you decide that 2 hours per day are spent on "nursing-like service". Now, simply multiply the number of days per year you receive attendant care by 2. Then multiply by the amount you pay your PA per hour. For example, let's say you received attendant services 300 days last year, and you paid your PA $4.75/hour:

300 days x 2 hours = 600 hours of nursing services

600 x $4.75 = $2,850 dollars of medical deduction for attendant care

Contact the IRS for other possible tax deductions like medical expenses, drugs, and home modifications that may give you a tax break.

It is important to keep records of when you mailed tax information and when you paid your PA. Creating a file is a good way to keep track of such things.

**Liability**

When employing personal assistants, liability is a critical factor. It is important to be very careful when having your personal assistant perform any activity, which could potentially injure you or your PA. If an injury occurs, and you own your own home, you should check your homeowner’s insurance policy. It will sometimes cover injuries in the home. It is also possible to upgrade your policy to cover liability. If you don't own your home it is possible for your PA to file for workman's compensation with the State. Some Personal Assistants have filed and won their cases with the workman's compensation board, but that is the exception rather than the rule. So remember to exercise the utmost caution with your PA in your home.

**Advocacy**

The major problem facing PA Employers in Illinois using the services of (DHS/ORS/HSP) is the low wage paid to PAs. Since most PA Employers are unable to pay for these services because the unemployment rate among people with disabilities is over 70%, it is imperative that your friends, family and neighbors get involved to raise the consciousness of the public and to work for an increase in personal assistance funding and other home and community based services. It has been estimated that 1.3 million young disabled people are institutionalized due to a lack of adequate supports within the community. In Illinois 88% of Long Term Care
taxpayer dollars goes to institutional placements. This institutional bias is costly, not just in terms of dollars, but also in terms of the human dignity taken from those "imprisoned" in institutional settings. Writing letters or calling your legislators urging them to increase funding for these programs is a start. Joining national advocacy groups like ADAPT (American Disabled for Attendant Programs Today) or local groups like TFAS (Task Force on Attendant Services), Progress Center’s PA Employers Consortium and The Family Support Network among others, helps to educate and raise awareness about the need for, and the cost effectiveness of, home and community based services. These, and other groups as a large coalition are currently working to divert the flow of funding back into the community and your participation is crucial. It is a fact that disability will touch every American at some time in their life. The PA team at Progress Center urges you to get involved now, to join with us and other members of the disabled community and let your voices be heard.
Appendix

In this section you will find:
1. Personal Assistant Application.
2. Employment Experience.
3. Reference Check Form.
5. Weekly Schedule.
6. Personal Care Activities.
7. Other Activities.
# Personal Assistant Application

**Date:**

<table>
<thead>
<tr>
<th>Name:</th>
<th>S.S.#</th>
</tr>
</thead>
<tbody>
<tr>
<td>Address:</td>
<td>City:</td>
</tr>
<tr>
<td>Phone:</td>
<td>Alt. Phone:</td>
</tr>
</tbody>
</table>

**Transportation:**

<table>
<thead>
<tr>
<th>Days Available:</th>
<th>M( )</th>
<th>T( )</th>
<th>W( )</th>
<th>Th( )</th>
<th>F( )</th>
<th>Sat( )</th>
<th>Sun( )</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Times Available:</th>
<th>AM( )</th>
<th>PM( )</th>
<th>Overnight:</th>
<th>Yes( )</th>
<th>No( )</th>
</tr>
</thead>
</table>

**Emergency Backup:**

<table>
<thead>
<tr>
<th>Yes( )</th>
<th>No( )</th>
</tr>
</thead>
</table>

**Comments:**

---

---
Employment Experience

Employer:

Address: Phone:

Position: Supervisor:

Date Employed: From: To: Reason for Leaving:

******************************************************************************

Employer:

Address: Phone:

Position: Supervisor:

Date Employed: From: To: Reason for Leaving:

******************************************************************************

Employer:

Address: Phone:

Position: Supervisor:

Date Employed: From: To: Reason for Leaving:

******************************************************************************

Applicant’s Statement

I certify that all information provided is true to the best of my knowledge.

(Signature of Applicant) (Date)
**Reference Check Form**

<table>
<thead>
<tr>
<th>Employer:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Address:</td>
</tr>
<tr>
<td>Phone:</td>
</tr>
<tr>
<td>Position:</td>
</tr>
<tr>
<td>Supervisor:</td>
</tr>
<tr>
<td>Date Employed:</td>
</tr>
<tr>
<td>From:</td>
</tr>
<tr>
<td>To:</td>
</tr>
<tr>
<td>Reason for Leaving:</td>
</tr>
<tr>
<td>What would you say is the applicant's strength?</td>
</tr>
<tr>
<td>What would you say is the applicant's weaknesses?</td>
</tr>
<tr>
<td>How would you compare applicant's work to the work of others who have had the same job?</td>
</tr>
<tr>
<td>How dependable was applicant when working for you?</td>
</tr>
<tr>
<td>Was applicant honest?</td>
</tr>
<tr>
<td>Did applicant complain very much about anything?</td>
</tr>
<tr>
<td>How did applicant let you know when there was something he or she didn't like or agree with?</td>
</tr>
<tr>
<td>How often was applicant late for work?</td>
</tr>
<tr>
<td>How often did applicant miss work?</td>
</tr>
<tr>
<td>What kind of driver was applicant (if appropriate to former job)?</td>
</tr>
<tr>
<td>Would you re-hire applicant?</td>
</tr>
</tbody>
</table>
Employment Contract

Employment Contract Between:

_______________________________  ________________________________
(Employer Name)  (Personal Assistant Name)

Work Schedule: (Circle the appropriate days)
Mon  Tue  Wed  Thur  Fri  Sat  Sun

Hours to be worked:

From:  To:

From:  To:

Salary:  Per Hour  Per Week  Per Month
Cash  Check  Withhold Tax: (Yes or No)

Benefits Provided for PA:

Room:  Yes  No

Meals:  Yes  No

Laundry (for live-in PA):  Yes  No

Utilities included (for live-in PA):  Yes  No

Utilities the PA must pay for:

Use of Personal Property items: (i.e. vehicle only as employer wants used):

____________________________________________________________________________
____________________________________________________________________________
____________________________________________________________________________

Fringe benefits: (Employer will pay for PA to accompany him or her to theater, restaurant, travel, entertainment:

____________________________________________________________________________
____________________________________________________________________________

Acceptable Social Behavior:
Swearing: Yes No
Smoking: Yes No
Drugs: Yes No
Drinking: Yes No
Overnight Guests: Yes No

**Employer’s Responsibilities:**
- Employer will not expect PA to stay past the agreed upon time (Except in emergency situations).
- Employer will be ready to work promptly upon the PA’s arrival.
- Employer will maintain records on PA’s performance.
- Employer will respect the personal assistant.

**Personal Assistant’s Responsibilities:**
- Personal Assistant will be on time.
- Personal Assistant will perform all duties as outlined by employer.
- Personal Assistant will complete the duties by the agreed-upon time.
- Personal Assistant will respect the confidentiality of the employer.
- Personal Assistant will respect the employer’s personal items.
- Personal Assistant will respect the employer.

**Absences:**
Both the employer and personal assistant must give at least ____ days advance notice of an interruption to the schedule. In case of an emergency, the employer and the personal assistant must notify each other as soon as possible.

**Termination:**

_____ number of days absent will result in termination.

_____ number of days tardy will result in termination.

Personal Assistant will be reminded _____ times of unacceptable behavior before being terminated. If the PA’s behavior is endangering the employer’s health or safety, the PA will be terminated without notice.

**Termination Notice:**
Each party shall give _____ weeks notice before termination except under extreme circumstances as mentioned above.
I, _______________________________ have agreed to work under the employ of,  
______________________________ as a personal assistant.  

Duties under this contract will consist of the following:

<table>
<thead>
<tr>
<th>Personal Care</th>
<th>Housekeeping</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bathing</td>
<td>Cooking</td>
</tr>
<tr>
<td>Washing Hair</td>
<td>Vacuuming</td>
</tr>
<tr>
<td>Dressing</td>
<td>Sweeping</td>
</tr>
<tr>
<td>Bladder Care</td>
<td>Mopping Floors</td>
</tr>
<tr>
<td>Brushing Teeth</td>
<td>Cleaning Bathroom</td>
</tr>
<tr>
<td>Grooming</td>
<td>Cleaning Kitchen</td>
</tr>
<tr>
<td>Transferring</td>
<td>Washing Dishes</td>
</tr>
<tr>
<td>Re-positioning</td>
<td>Dusting</td>
</tr>
<tr>
<td>Range of motion</td>
<td>Polishing Furniture</td>
</tr>
<tr>
<td>Skin Care</td>
<td>Shopping</td>
</tr>
<tr>
<td>Equipment Cleaning / Maintenance</td>
<td>Laundry</td>
</tr>
<tr>
<td>(includes wheelchair, commode, bed)</td>
<td>(includes ironing)</td>
</tr>
<tr>
<td>Assistance with Oxygen use</td>
<td>Watering Plants</td>
</tr>
<tr>
<td></td>
<td>Daily Trash Removal</td>
</tr>
<tr>
<td></td>
<td>Driving</td>
</tr>
</tbody>
</table>

My employment will be for a maximum of _____________ approved hours per week. Hours to  
be worked will be __________ and I have agreed to work __________ days per week for  
$__________ per hour. I have received and fully understand the list of guidelines and will  
follow them to the best of my ability. I further understand that any or all terms of this contract  
may be subject to renewal or change upon agreement.  

________________________________________  ____________________  
(Personal Assistant)                     (Date)                      

________________________________________  ____________________  
( Employer)                              (Date)                       


## Weekly Schedule

<table>
<thead>
<tr>
<th>Monday</th>
<th>Tuesday</th>
<th>Wednesday</th>
<th>Thursday</th>
<th>Friday</th>
<th>Saturday</th>
<th>Sunday</th>
</tr>
</thead>
<tbody>
<tr>
<td>Morning</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Afternoon</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Evening</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
# Personal Care Activities

<table>
<thead>
<tr>
<th>Who will do?</th>
<th>How long does it take?</th>
<th>Daily (D) or day of week to be performed</th>
</tr>
</thead>
<tbody>
<tr>
<td>S=Self</td>
<td>Morning</td>
<td>M A E N</td>
</tr>
<tr>
<td>F=Family</td>
<td>Afternoon</td>
<td></td>
</tr>
<tr>
<td>PA=PA</td>
<td>Evening</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Night</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Activity</th>
<th>M</th>
<th>A</th>
<th>E</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Brushing Teeth</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Shaving</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Make-Up</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dressing</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Transfer: Bed</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Wheelchair</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tub/Shower</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Turning in Bed</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medication</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Eating</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Exercise</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bathing</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bowel Program</td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Bladder Program</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Undressing</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Preparation for sleep</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
## Other Activities

<table>
<thead>
<tr>
<th>Who will do?</th>
<th>How long does it take?</th>
<th>Daily (D) or day of week to be performed</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>M</td>
</tr>
<tr>
<td>Recreation (Fun!)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Household Details (Bills, Grocery List, etc.)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Laundry</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Shopping</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Meal Preparation:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Breakfast</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lunch</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dinner</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Meal Clean-Up:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Breakfast</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lunch</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dinner</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cleaning:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bedroom</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bathroom</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Kitchen</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Floors</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dusting</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mopping</td>
<td></td>
<td></td>
</tr>
<tr>
<td>School, Job, Etc.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Driving / Mobility</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>