

DHS/ORS Personal Assistant Training Program: Report on Personal Assistant (PA) Input

To engage Personal Assistants in the design of a training program that will best meet their needs, SEIU has initially conducted two outreach efforts:

- ❖ **Surveys** – Surveys were mailed to all Personal Assistants working in the DHS/ORS Home Services Program in the spring of 2011. As of June 11th, 2,040 PAs have returned their surveys, and their input is captured in the report below.
- ❖ **Focus Groups** – To probe more deeply, survey respondents who expressed interest in the training program were invited to participate in Focus Groups that were held in Rockford and Chicago on June 8th and 9th, 2011. Thirty-eight PAs with a wide range of experiences participated in these sessions. Their input is also woven into this report.

I. The Case for Personal Assistant Training

2,040 Personal Assistants responded to a survey conducted by SEIU. Data from survey results indicate that:

- **68% of PAs have received no training to do their job as a Personal Assistant.**
- **78% of PAs would like to receive training to do their job as a Personal Assistant.**

Survey respondents and focus group participants shared the following thoughts and comments:

- *"I'm so pleased that training is being offered. It's been a long time coming. Not only will the customers receive better quality care but PAs will hopefully strive for growth for themselves."* - Amy Price, PA- Antioch, IL
- *"We really need all of these training classes. All of them are vital to PAs becoming better at their jobs."* – Lorraine Johnson, PA (2 years)- Chicago, IL
- *"I'm truly grateful for the chance to better my experience in helping the consumer in any manner at all. Please give me a chance to learn more that will help me be one of the best PAs ever. I will work hard to obtain all knowledge as I possibly can."* - Ronald Shorter, PA (1 year), Chicago IL
- *"The training is one of the best ideas."* – Stephen Collins, PA (4 years)- Rockford, IL
- *All these ideas are great to receive training for. I am looking forward to receiving PA training to improve my work skills"* – Adela Mendoza, PA- Frankfort, IL

- *"I think the training program will help improve our skills in what's most essential to improve our working skills with our customer relationship & healthcare."* - Veronica Jones, PA (4 years)- Chicago, IL
- *"I would like to receive all training I can get."* -Michael Lopez, PA- Granite City, IL
- *I would like to learn as much as possible to help fulfill my duties/requirements as a Personal Assistant."*– Jarvis Allen, PA- Freeport, IL

In the absence of a Home Services training program, PAs have relied on prior training they have received in a variety of settings, and have sought out their own sources of information, support and mentorship.

Many PAs reported having previous experience working at Home Care Agencies¹, Home Health Agencies, and Nursing Homes, among other settings; those PAs felt that their previous training and experience had helped them prepare for their role in positive ways.

- *When I first worked through DRS, I didn't know if my consumer could walk or talk or get out of bed. You look to someone in the household to tell you what's going on. I didn't know what to expect when I went there. If I didn't have CNA skills prior to that, I wouldn't have known what to do.*

PAs have also sought out information, advice and training from a myriad of less formal sources. The majority of PAs in the Focus Groups spoke of searching out learning and support in multiple ways, including from their consumer employers, from medical professionals, from books, video, magazines and the internet, and from support groups.

- *My consumer has helped me a lot to help her, because you don't get any training.*
- *I talked to doctor and nurses... The nurses that come in to my consumer's home trained me.*
- *I got training in the hospital, because I wanted my consumer to have the same training when he came home.*
- *In a rehabilitation center; I saw what they were doing with him and how they were lifting him. I trained myself to do after watching them. A nurse used to come and she would show me how to clean and dress his wounds. Never had any official training, I just looked and learned. I read up and get books and videos from the library, and look on the internet, and figured out things myself.*
- *I got videos at the library about getting people out of bed, how to sit up. You can find out how to approach people w/ bipolar, schizophrenia, Alzheimer's.*
- *I subscribe to Multiple Sclerosis magazine.*
- *I have an Alzheimer's support group I go to. Without these people I'm not sure what I would have done. I've been with them for 1.5 years.*

¹ Illinois Department on Aging Community Care Program regulations require that Agencies provide Home Care Aides with 24 hours of pre-service training and 12 hours of annual in-service training.

Recommendations for Training Program Design

SCHEDULING OF TRAININGS

1. **The Best Days & Times of the Week for Training** – Survey results were fairly evenly split across all possible days and times, although PAs indicated that weekends were most preferred.
 - **21% of PAs said weekdays during the morning**
 - **22% of PAs said weekdays during the afternoon**
 - **26% of PAs said weekdays during the evening**
 - **31% of PAs said weekends**

The majority of respondents indicated that multiple times would make attending training most convenient for them. Focus Group participants confirmed the need for offering training at a variety of different times and on weekends to accommodate widely varying schedules.

2. **Length of Training Sessions & Option for “Modular” Approach** - Focus group participants felt that shorter sessions will best fit PAs’ busy schedules. They reported that training sessions lasting 2 to 3 hours would be accessible to the most PAs, because many do not have the time to fit in longer classes.
 - In Focus Groups, many PAs felt that using a modular, short-session approach that allowed the same topic to be available at various days and times during the week would make training most accessible. Some suggested there be *a menu of different types of topics, each module lasting at least an hour*. Some focus group participants indicated that the scheduling of the Focus Group was a good model for scheduling training, whereby participants were given the option of a 3 hour session on Wednesday evening *or* Thursday evening.

ADVANCE NOTICE & TRAINING OFFERED LOCALLY

3. **Survey Respondents & Focus Group Participants Emphasized the Need for Advance Notification of Class Offerings.** Because of the varying nature of their schedules (“sometimes we work in the morning, sometimes we work in the evening”), PA’s felt that advance notice, offered through a variety of means- including notification through the mail- would maximize their ability to participate. Respondents indicated that advance notice would enable them to arrange for child care, food preparation for significant others, travel arrangements, coverage for their consumer, and other necessary arrangements.

Many PAs stressed the importance of having the training available locally in cities and towns across Illinois in order to minimize travel time and cost of gas. Specifically, most comments asked for training outside of Chicago.

OFFERING CERTIFICATES

4. **Certificates** were important to many survey respondents and Focus Group participants. When asked, *“What is it that will make the majority of the PA’s be able and want to attend the training?”* PAs said the topics offered and *“A certificate at the end of the class about what you’ve learned.”*

Many PAs felt that a certificate offered at the completion of training classes, or at the completion of a series of training classes, would encourage PAs to attend, and allow them to demonstrate to their consumer or to future employers that they received training.

TRAINING METHODS

5. In the Focus Groups, PAs expressed strong opinions about how to deliver effective training. Suggestions ranged from the plea in a survey response of *“More than videos,”* (though three PAs specifically asked for videos) to calls for approaches that appealed to the variety of learning styles people have – auditory, visual and kinetic.

The majority of PAs in the focus groups felt that the training should be participatory, with opportunity for discussion and back-and-forth engagement, rather than lecture-style presentations.

- a) **Hands-on training** that includes demonstrations and role plays, and then gives participants the opportunity to practice their skills and approaches was suggested by a dozen Focus Group participants.
- *When you get the material, you have to play the role. You have to actually practice what you’ve seen or read on paper and see how it works for you.*
 - *The best way is hands- on demonstrations training, where you are able to apply what you’re reading.*
 - *It might seem easy, but you actually have to do it and demonstrate to make sure you’re doing it the right way.*
 - *Best to learn by example. You have to learn what’s required and an experienced person who shows the steps for you, and you prove that you can demonstrate those steps and you’ve learned. The modeling, and then getting feedback.*
- b) **Using visual displays and offering handouts with take-away information** was recommended by many PAs, and these examples were cited:
- *For CPR/1st Aid, we do it in the class, and then they give us a handout reminder to take home and post on the refrigerator to remind you of the steps.*
 - *If I’m in a class I work so much better if they have stuff up on the board, step 1, 2, 3 and a handout.*
- c) Two PAs spoke about doing **in-home training**, one noting that this was important *“because each consumer is different; what works for one doesn’t always work for another.”*

- d) One Focus Group participant suggested **computer-based training**, and others quickly jumped in to say many PAs don't have computer, and they thought it was better to learn as a group. One survey respondent noted, *"If something could be done on-line, I would be interested; I have another full time job."*
6. **Joint Training with Consumers/Training for Consumers?** A survey respondent suggested that it would be good to have *"combined training for customers and their PA on expectations and duties. Many customers are unable to advocate or have little training in managing employees."* In Focus Groups, PAs liked the potential benefits of joint training with their consumers, including that consumers would have a chance to be engaged in the community and learn what's going on with PAs and that PAs could learn about consumers' specific preferences.

The significant drawback was that PAs felt they couldn't speak of all the issues they might want to address with their consumers present. One thought was that it "depends on the topic if the consumer should be included. Not all topics apply to everybody."

Some PAs commented in the survey that they would like more training available for their consumers and their families, including training to help their consumer learn "how to hire PA's and what to ask potential workers," training for consumers to be better employers, and training in managing the stress of living with disability and progressive diseases.

TRAINING CONTENT

7. **Survey Results** -- Respondents were asked to rank specific "Basic" and "Home Care" skill topics on a scale from 1 (most interesting) to 6 or 7 (least interesting). The results of those rankings, along with their average score, are as follows:²

BASICS

- a) Disability Awareness & Supporting my Consumer's Independence (2.03)
- b) Rules & Regulations of the DHS/ORS Home Services Program (2.2)
- c) The Employment Relationship: How to Work Together (2.36)
- d) How to Improve Communication with my Consumer Employer & Resolve Problems (2.61)
- e) How to Work as a PA & Interviewing Tips (2.73)
- f) GED Preparation and Computer Basics (3.5)

HOME CARE SKILLS

- a) CPR & First Aid (2.07)
- b) Medication Safety (2.59)
- c) Infection Control and Universal Precautions (2.88)

² It is of note that all topics had fairly high rankings, with each one ranked a "1" by at least a 100 respondents.

- d) Nutrition and meal planning and preparation (3.02)
- e) Proper lifting and transfer techniques (3.03)
- f) Usage of Adaptive Equipment (3.36)
- g) Techniques in Personal Care (3.49)

DETAIL ON SURVEY RESULTS: Focus group participants and many survey respondents provided greater detail on the types of training topics they thought would be most useful.

Basics

- a) **Rules & Regulations of the DHS/ORIS Home Services Program:** Focus Group discussions reinforced that new as well as incumbent Personal Assistants would benefit from a more thorough orientation to the Home Services Program system, and to their roles and responsibilities within that system. Many PAs expressed concern that they lack knowledge of basic rules & regulations, and don't know who to contact for information. PAs experience confusion around the responsibilities of their consumer employer versus DHS/ORIS' role as employer.
- *It would be good to have training on how to do timesheets and how the program works.*
 - *Hours need to be explained better; who do I contact when I am made to work more than the allowed hours?*
 - *Who do I talk to about when am I eligible for benefits?*
 - *When I first started, I had to wait to receive my first paycheck; I worked in June and I didn't get paid until July. I didn't know that.*
 - *I didn't even know who I was working for – DORS or my Consumer.*
 - *We need training on the roles of the PA, Access Living, the consumer, who's supposed to do what?*

Clarifying Roles , Responsibilities and Boundaries: PA's indicated in surveys and in focus groups a degree of uncertainty about their roles and responsibilities as PAs, and indicated their desire for clarification around their job duties and limitations. PAs are not clear, and do not experience consumers as being clear about exactly what are appropriate expectations and boundaries on their roles. Respondents shared uncertainties about the PA's role in transporting consumers, the extent of housekeeping responsibilities, whether PAs are responsible for caring for pets and animals, what their responsibilities are when multiple consumers or live in the household, their role in relation to family members living in the home or visiting guests, and more:

- *Duties need to be more defined! I would like to know all of my duties as a Personal Assistant, and what are the overall expectations of PA's. DRS should give us a list.*
- *I want to know what you're supposed to do- and not do- for your consumer.*

- *We need more information on policy and procedures of taking care of and supporting consumers.*
- *There should be limits of what a PA should do and not do; Example: A PA should not be a servant to a client's guests.*
- *There should be a checklist of everything PAs can do in a consumer's home. There should be generics and specifics. The generic is Xerox that everybody gets, the specific can be handwritten.*
- *I go to their house, and they tell me to wash their baseboards. Baseboards? But then DRS has them believing that I come in and do whatever they tell me.*
- *Maybe a pamphlet can be made for the customers letting them know the Do's and Don't of the PA's and what the PA's job description is, and make the customer aware that we are only there for their needs, and not the needs of other residents living there.*
- *One person asked me to clean her oven, when I am there to fix the breakfast and lunch for her husband, do light housework, and wash his dishes only.*

PAs wondered how to respond to exposure to second-hand smoke in the consumer's house, to use of illegal drugs by persons in the home, and to being asked to administer medicines by consumers. They also had very specific concerns, such as:

- *Disclosure of client's personal information to caseworker in regards to fraud.*
- *When to contact a healthcare professional.*

b) The Employment Relationship: How to Work Together: In Focus Groups, many PAs stressed the qualities that PAs need to do their job well included a positive and pleasant attitude and personality, patience, good listening and communication, calmness, sensitivity, following the Golden Rule, and keeping a focus on the importance of the client. One PA noted that a good PA involves herself in learning her consumers' interests, and in knowing whether the consumer is happy with the services. They felt that training could help people develop these qualities.

PAs said it would be helpful to receive training about having an effective first interview with consumers to establish clear expectations and a good relationship, and felt that PAs and Consumers should be provided with interview questions or checklists of duties to facilitate the interviews. Some PAs mentioned that there should be advance discussion and agreement with the Consumer on a "Back up Plan" if the PA is not able to work.

Many PAs stressed the importance of Professionalism, and the need for training to reinforce the importance of PA's arriving on time or calling to say they will be late, completing all duties on time, dressing appropriately, doing your best and always being willing to improve your skills to the fullest.

Consumer Self-Direction: As one PA asserted at a Focus Group and others nodded in agreement, *"You should be trained so that you don't feel sorry for people, not at all. We can't go in like we know it all. We go in and keep them in charge, not*

the PA." Another woman said, *"We need to be taught how to communicate. I can't say I know what's best for you, or your way is not the right way. I went into some people with that attitude. I hope these trainings will enhance my people skills, my communication skills."* One PA said she'd like to learn, *"How to ensure consumer is active in their own care. Giving consumers the right to choose."*

When asked if having core training might undermine PAs' understanding that their consumers would train them in providing supports and services they way they wanted them delivered, PAs in one Focus Group were confident that it wouldn't. They said:

- *A lot of people are not comfortable, so it's good to give them training because they will be more comfortable in knowing the job.*
- *When I was in nursing school, you learned generalized care. You still had your consumer give you the specific training that makes it individualized, tailor made to them. But the general training, is the foundation to build on.*

c) How to Improve Communication with my Consumer Employer and Resolve Problems:

Based on forty survey comments and extensive Focus Group discussion, this is a major issue for PAs, and one that they believe training can help immensely. *"Communication is vital. It is a skill to be learned and applied for effective service provision. Not enough can be said, when addressing and resolving problems."*

- *Communication skills are important with patient and coworkers. Kindness to family members who enter the home of patient especially elderly relatives.*

Two or three PAs also mentioned wanting help communicating with non-verbal consumers.

Home Care Skills

- a) **CPR & First Aid :** Survey respondents and focus group participants expressed a high degree of interest in CPR and First Aid training. In Focus Groups, many PAs expressed their belief that this was an essential training for all PAs to receive, and some thought it ought to be mandatory.
- b) **Medication Safety:** In the Focus Groups, one PA said, *"I would like to see PAs trained how to effectively and tactfully dissuade consumers from making unreasonable requests of us, regarding administration of medicine that we are not trained to do nor required to do."* Another was concerned about, *"seeing that consumers take medication."* And another wanted to learn about the *"effects of blended medications."*
- c) **Infection Control and Universal Precautions:** One survey respondent commented that, *"I am surprised the State does not require Infection Control/Universal precautions as part of employment prerequisites."*

- d) **Nutrition and meal planning and preparation:** Although ranked lower overall than the topics above, Nutrition and Meal Planning was the focus of seven survey comments and a great deal of discussion in the Focus Groups. Hopes ranged from, *"I would like to learn how to cook for my clients,"* and *"How do you develop meals that people want to eat?"* to concerns about being able to offer nutritious options for people with a variety of health concerns, including heart disease and depression. The single biggest point of discussion was around learning about diet and nutrition for consumers with diabetes.
- e) **Proper lifting and transfer techniques:** Although this topic had a slightly lower survey ranking, Proper Lifting & Transfer was expressed as a concern by many in the Focus Groups. PAs were concerned about injuring themselves and injuring their consumers. They also wanted to understand when to use Hoyer lifts, gait belts and boards. One PA noted:
- *I haven't had any training. I would like to learn about transportation and moving her around, especially hot weather like these last few days, it really hurts her. Main thing is pain. I do a lot of massaging, Jacuzzi baths.*
- f) **Usage of Adaptive Equipment:** Numerous respondents had questions around how to find, purchase or lease, and repair equipment, and whether there were existing resources to assist with obtaining needed equipment.

In addition, PAs at the Focus Groups discussed needing training on using adaptive, *"Especially wheelchair, Hoyer lift, gait belt, medical equipment, adaptive equipment. They only give you a crash course with the equipment in the house."* More than one participant expressed concern about finding, buying and maintaining equipment as well:

- *"PA's should be in charge of figuring out the household needs. My [consumer] had trouble getting out of the tub; she didn't know she could get the grab bars. She thought it would come out of her pocket. Also, for people who need specialized toilet, the PA should know where to call.*
 - *My consumer had a Hoyer lift in his home. But he didn't know how to use it, and neither did I. So we never used it.*
 - *We have a lift outside the home, it needs repairs. Who do I call for this?*
- g) **Techniques in Personal Care:** This topic may have received the lowest ranking because it is so broad. In survey comments and in focus groups, PAs expressed the need for enhanced skills in a wide variety of specific areas. One survey respondent said she wanted to be prepared to *"Be able to anything the client asks about his/her care that the client feels you can do, e.g. catheter care, medication management etc."* Several survey respondents indicated that Bathing was an important aspect of personal care, and highlighted the importance of knowing techniques and products to bathe and wash the consumer's hair while they remain in bed. Another PA was concerned that "everyone seems to forget to do oral health, i.e. brushing & or denture care."

One PA wanted training on the *"Proper way to put my consumer's clothes on because when they're in a position like a fetus, and it can be very painful."*

8. **Additional Topics of Interest to PAs in Surveys and Focus Groups:**

321 PAs added comments to their surveys, many with suggestions of training topics that they felt were critically important. In the Focus Groups, PAs echoed many of these suggestions and itemized some.

- a) **Credentialing, Licensing and Career Ladders, and Certified Nursing Assistant (CNA) Training**-- Over 30 respondents said that they would like to receive certification or licensing for training they participated in, including being certified as PAs, and/or that they would like to pursue career ladders.

Twenty survey respondents asked specifically for training and to become CNAs, some of whom hoped to move forward with their careers.

18 mentioned LPN, RN or other healthcare fields such as PT and OT. One commented that she would like a credential that was recognized by more potential employers.

- b) **How to handle challenging consumer behaviors or consumers' mental and emotional challenges** – Twenty survey and many more Focus Group comments highlight concerns in this area. As a PA said, *"Mental health training would help me with my two consumers."* Others wanted training in *"Understanding the emotional and physical needs of the client,"* and another in the *"Psychological, psychosocial needs of the consumer."* One PA explained:

- *"I try to sit and listen with her. She goes to coping groups to learn coping skills, but I want to learn how I can learn from her how to help her get through it."*

Supporting consumers through emotional challenges:

- *It would be great to receive training relating to the patients emotional well-being. Many disabled individuals are depressed and/or emotionally affected by their situation. It would be great to get tips & techniques for coping with and improving their mood.*
- *I would like training on how to deal with emotional problems and depression in consumers at home, and how to deal with consumer employers who struggle with anxiety and panic disorders.*
- *How to react to consumers' aggression and how to deal with consumers' anger management issues.*
- *If a consumer employer becomes agitated, what is the most effective way to diffuse the situation in regards to PA and consumer safety.*
- *How to not be combative even in the most severe circumstances, remembering we are their most practical solution for their needs.*
- *I would like to hear more information on helping my patient be able to help herself when she can. She is still relatively young and regularly depressed with*

her decline toward possible facility care. How should I go about helping her cope?

- *Dealing with and helping aid patients with their emotional needs- such as moodiness, aggression, obstinacy, and resistance at times during care giving.*
- *How to deal with mood swings of brain-damaged individuals (particularly stroke survivors).*
- *Learn techniques to re-approach and redirect.*

- c) **Family members and others in home** – Ten survey comments and a great deal of discussion at the Focus Groups attest to the level of concern PAs have regarding this topic and how much they would value training and other supports to assist them with the challenges they face in this regard. One PA mentioned wanting advice on how to handle it when there are two consumers in a house.

Family members: Many PAs spoke generally about wanting training to learn how to work effectively with family members. One wanted to learn *"teaching techniques,"* and a second agreed, *"We need to know how to approach and teach families. I think we need to teach families a lot."* Some PAs specifically talked about needing help *"dealing with difficult family members."* As some PAs described it:

- *I worked at nursing homes when I got my CNA license. Working at a nursing home versus someone's actual dwelling is a completely different experience – especially when family is present in the household. You witness family issues and family arguments. This is something...*
- *Once I started getting paid, the husband wanted me to start doing things for the family. I think I overreacted a lot when he first approached me."*
- *We need training and information on how much families should be involved and their expectations relating to your consumer when they also live in the house.*

Guests visiting the consumers' homes - Some PAs are concerned for their consumers, others for themselves. One PA asked what to do when she saw guests *"freeloading"* on her consumer. One PA told a story of a friend who was assaulted by a guest. Another told this story:

- *You should have training for how to deal with other people in the house. There was somebody who was getting high in the house when I was there. I asked him please, wait till my 3 hours are over and I leave, but he kept doing it. So I said I had to go. Sometimes the other people are disrespectful. You've got to be clear, that I'm here for the consumer, I'm not here for you."*

- d) **Community Inclusion and Services** — Nine PAs expressed interest in supporting consumers to participate in community activities and access community services. They asked for tips and information on free recreational opportunities to be made available, not merely training. In addition, they wanted to know about services *"to help consumers in making a better living for themselves and their children or*

families, as well as PT/OT services." Two requested training on developmentally appropriate activities and social awareness.

- *As DRS workers, we should be supplied with lists of programs, like day care. So I can find someone who is just like her, so she can communicate with someone who is like her.*
 - *What type activities you can do during the day, given the different disability. Like if someone has CP, what is a good activity to do with them.*
 - There should be something like an information fair to get referrals on resources and other information
- e) **Physical Therapy** -- Six survey respondents noted that that PT would be beneficial so that they could help their consumers with exercises such as leg lifts and work with hands and arms. One asked for training customized to specific disabilities or needs. Focus Group participants also mentioned this. Other comments included:
- *My patient is interested in physical exercises I might be able to help him with that would be safe for him and improve his muscle condition.*
 - *I have found that participating in physical occupational & speech therapy in outpatient facilities and in home care tremendously improves my skills in adapting to my clients' disabilities and providing consistent quality overall care.*
 - *Exercises, not like a doctor's therapy session, but programs on range of motion.*
- f) **Home Cleaning** – Two surveys comments expressed concern about "*seeing that the consumer's house stays clean,*" and wanting to learn how to properly clean and disinfect areas. A Focus Group participant noted that, "*Not everyone knows how to clean. Sometimes you get a client that is not used to clean habits.*" Another wanted to learn "*how to clean the house clean and sanitize the filth and dirt.*"
- g) **Recordkeeping/Role in Care Team** – Three survey respondents felt that it was important for PAs to track things such as, "*times/dates if consumer falls and gets bruises from falls, medical files and prescriptions.*" As one noted, "*There should be some sort of standardized paperwork to keep track of consumers' medical history.*" Two linked this to PAs having a role in communicating with doctors.
- h) **Budgeting and financial management and supports** – Four PAs asked for training in this topic, with one asking, "Are there laws on the teaching money management to clients?" Another hoped for "Ideas on having consumer not being dependent on PA for money." Other respondents wanted to know how to assist consumers in getting financial assistance for medications and accessing other benefits they may qualify for, and "*how much help we can be financially to our employers.*"
- i) **Death and dying** – Three PAs asked for this topic in comments on the survey. One respondent hoped for help in handling personal grief.
- j) **Assisting consumers who are bedridden** – Five Focus Group participants mentioned wanting skills particularly for helping patients while they were in their

beds, including, *"It would be very helpful to be trained in how to care for consumers who are bedridden."* Three wanted to learn bed-making. *"We need to learn to change the sheets while they're in the bed."*

k) **Handling medical and other emergencies, and disaster response**

- What if the consumer falls?
- When you're working in a consumer's home, it's helpful when they supply you with who are all their doctors, all their meds, contact information for family members. As a PA, you need to be prepared if there is an emergency.

l) **Safety: basic precautions and procedures** – Two PAs mentioned safety. One said, *"To provide safe and secure services for the people you're supporting, how to move around safely for them and yourself."* The second said, *"I believe that some type of safety techniques for the PA would be wonderful."*

m) **Training in medical tasks** – Some PAs indicated they wanted training in topics such as monitoring blood pressure and blood levels, taking temperatures, administering shots, oxygen and ventilator training, remedies for bed sores and rashes, and information on the flu season and available shots.

n) **Wider awareness of types of disabilities and their care needs** – A handful of comments were written into surveys asking for more specific information about the various disabilities and diseases that consumers had, including dementia, muscular dystrophy, diabetes, and more. They said:

- *I took on a second consumer, an older gentleman. I later found out after several episodes he had dementia/hoarding issues. I was not trained or given forewarning to his conditions. I was not prepared and did not know how to handle this.*
- *My employer has MD. I would like more information on the long term disabling disease, e.g. what happens from 10 years on.*

In Focus Groups, PAs went into more detail and expressed great concern about learning about their consumers' disabilities, and about the diseases and injuries that caused their consumers' disabilities. Many worked for consumers with multiple disabilities, and this further complicated their efforts to understand how to provide the best services and supports. They repeatedly expressed how having a better understanding of what their consumer was going through and what to expect over time would reduce their stress and allow them to provide better services and supports. As they noted:

- *My people are destroyed because of lack of knowledge. I need to know the diagnosis, the symptoms, because I cannot help that person if I don't know what they've got or what they're going through.*
- *We should find out what was the medical condition of the person before we go into the home.*

- *We need to have classes that cover certain diseases – what are the various levels the consumers can experience, seizure activity, what to look for, what would constitute a 911 call, how you approach specifics and how to discuss conditions without offending consumers.*

Diseases and conditions that PAs in Focus Groups were interested in learning more about included the following:

- | | |
|---|---|
| 1) Aneurism | 21) Mental illness, psychiatric problems. Specific issues included: bipolar and anxiety attacks |
| 2) Arthritis | 22) Multiple sclerosis |
| 3) Autism | 23) Neuropathy |
| 4) Blindness | 24) Nerve disease |
| 5) Bone disease | 25) Obesity |
| 6) Bowel obstruction | 26) Paralysis – one side, paraplegia, quadriplegia – |
| 7) Cancer | 27) Polymyositis |
| 8) Cerebral Palsy | 28) Rheumatoid arthritis |
| 9) Dementia and Alzheimer’s | 29) Scoliosis |
| 10) Developmental delay and disability | 30) Seizures |
| 11) Diabetes | 31) Sleep apnea |
| 12) Down Syndrome | 32) Sore care – bed sores and others |
| 13) Hearing impairment | 33) Spasms |
| 14) HIV/AIDS | 34) Stroke |
| 15) Hodgkin’s disease | 35) Thyroid condition |
| 16) Heart and blood diseases and conditions | 36) Traumatic Brain Injury (TBI) |
| 17) Kidney failure | 37) Wound Care |
| 18) Leukemia | |
| 19) Liver disease | |
| 20) Lupus | |

o) **Self-care** – There were a number of survey comments about coping with stress that didn’t specify if they were referring to the consumers, the PAs, or both. In Focus Groups, PAs’ needs for skills and strategies to help themselves feel strong and positive came through. Among the comments, PAs said:

- *Any suggestions for stress relief, including dealing with the stress relating to caring for consumers with mental disabilities*
- *Dealing with my own mental stress due to the care and problems of the consumer’s progression of illness*
- *I would like information on respite care and support groups for caregivers .*

p) **Family caregivers’ needs** – A number of participants in the Focus Groups were family members of their consumers. When asked if they had specific training and

support needs, they expressed interest in improving their communication skills, along with understanding the impact on the whole family of supporting one member with special needs.

- *I need training for handling the emotional part. When you find out that your loved one has different needs going on, you don't know how to process or deal with it; you're going thru the motions and you're bottling your own emotions up. I went to the therapist for my son, but never a therapist for me.*
- *I think it's alienated my daughter because she thinks I love my son more than I love her for the amount of attention we've had to give him versus her. We in the home are taking care of our loved ones, we have to know when it's time to take care of the others in the home. We need to address the issues that come up with other family members, or we can be causing a bigger problem in the family. We need to educate ourselves on how we're affected, our mental health, we get depressed and anxious, and we need help managing the rest—the whole family.*
- *In my own family, there is constant friction. I'm sure a lot of the training is about communication.*
- *I believe there is a ripple effect in the family when someone needs extra care. Others don't understand when they see their mother crying. The kids are so innocent, they just want to help. Sometimes the kids think it's their fault. You have to explain it's just the illness.*
- *When you're dealing with a consumer who lives at home with you, it's 24-7. Different from when you go to their house, because you can't leave.*
- *Communications: we have so many barriers in our communication. You have to phrase, re-phrase, paraphrase, and reflect a feeling, like you're doing here.*
- *For family members- it's overwhelming; we give up a lot of our personal life and we're not being appreciated. I need some type of support too, as well as she needs.*
- *If there's any training that would help us help each other I could welcome that.*

9. **Peer Mentor Program:** 28% of survey respondents (770 PAs) expressed interest in receiving training to become Peer Mentors. Experienced PAs in the Focus Groups also were interesting being mentors.

One PA called the idea of a Peer Mentor Program, "*Outstanding.*" Another said, "*As we keep going forth the mentor will be greatly needed. We are helping each other.*"

Mentors could also help PAs understand the DRS system – how to fill out time sheets, make sense of the PA packet, follow service plans, divide up hours effectively among the supports that need to be provided, and advising on who to contact for different information. A number of PAs also mentioned having mentors serve as back-up PAs and helping to cover schedules.

- a) **Role of Peer Mentor** – PAs thought that Mentors could help PAs improve their knowledge and skills as caregivers, but they were also enthusiastic about their role as someone to talk to and release stress with, given the isolated nature of their work as PAs working in the home.
- *Peer Mentor could offer suggestions on how to become a better caregiver and better support the customer.*
 - *Like with MS, everything goes wrong. MS Society doesn't know what's going on, it's not in the book, then I could call the Mentor.*
 - *The Mentor could be a sounding board, and could suggest different ways of doing things that I didn't already think of. Mentor could be someone to talk to, who can be a listening ear, like a buddy system.*
 - *Especially when you're new at this, sometimes you need somebody who is not going to judge you and going to share their way of doing things.*
 - *Mentor is someone to help you cope with the emotional stress of caring for someone with a disability You need support for that too.*
 - *Would be good to reach out to someone who is a mentor -- especially caregivers who care for family members where it's 24/7, because caregivers are going through a whole lot, mentally and emotionally.*

- b) **Peer Mentor Qualifications** – PAs set high standards for mentors. All wanted experienced PAs, though there were different ideas about how much previous experience was necessary. Mentors had to be people who had *"been down that road, they've been there."* Mentors need to be people who really learn themselves from their experiences and those of others too. *"They would need to know about other people's situations, not just their own. They would have to learn about each situation, and be a well-rounded, good listener."*

Qualities mentors must possess include patience, sincerity, dependability, *"the willingness to learn, humility,"* and *"a positive attitude at all times."* *"Someone who loves what they do."* PAs who *"have to have passion for what they do."* *"They need to put morals and ethics first."*

A mentor also *"needs to be a good communicator, who has a good approach to other people. Needs to know how to present, can't be like a lecturer in a lecture hall."*

PAs wanted mentors to be trained and to have been through PA programs that are offered. Mentors *"need to be up to date."*

Another PA suggested that it would be good if mentors were *"People that have consumers with the disability that you're dealing with, for example, down syndrome."*

- c) **PAs are proud of and would like to share their training and experience** – The responses to the survey from PAs who would like to be mentors reflected this, along with comments from thirteen survey respondents outlining their individual

expertise. Areas included home care with hospice patient; military and police/fire department medical training; training and experience with feeding tubes, phlebotomy, intubation and extubation tubes, daily medication; and a Master's degree in workforce education. One PA is a mobility and transfer coach at a major hospital, and CPR & First Aid Certified.

Summary Results from 2,040 Survey Respondents ▪ As of 6-11-2011

1. Length of Experience –

- PAs' length of service varied widely, but averaged 5.4 years among the 1,927 who gave responses.

2. PAs' Education Levels & Certifications/ Licensures–

- PAs have varying levels of education, with 44% having attended some high school or having a High School diploma or GED, and nearly 49% having some college or a college degree.
- 16% of PAs responded that they are Certified Nursing Assistants;
- 2% of PAs responded that they are RN's, LPN's, or PT/OT's.

3. Consumers –

- 84% of PAs responded that they provide homecare for 1 consumer
- 10% of PAs responded that they provide homecare for 2 consumers
- 4% of PAs responded that they provide homecare for 3 or more consumers

4. Interest in Additional Work –

- 68% of respondents indicated they would like to be hired as a PA by other consumers.

5. Safety on the Job –

- 5% of survey respondents reported being injured on the job.