



DHS/ORS Personal Assistant Training Program: Report on Consumers' Input

Home Services Consumers –On June 28 and June 30, 2011, interviews were conducted with six Home Services Program consumers. (Centers for Independent Living were asked to identify consumers to participate.) This Report summarizes their input.

Consumer Participants:

- Rachel Silver (Access Living) ▪ Gloria Gray (Access Living) ▪ Carrie Kaufman (Access Living)
- Daniel Strohbeck (Impact) ▪ Kathy Stiles (Impact) ▪ Mike Ervin (Access Living)

Overarching Thoughts – Home Services Program Consumers emphasized the following overarching ideas:

1. **Training should reinforce consumer control** and direction and deepen PAs' understanding of their role as the consumers' employee. Training based in the medical model would be counterproductive.
 - *When I put in an ad for CNAs, I make a joke that I won't hold it against them that they're CNAs. I think CNA training is more of a hindrance. It's based on a medical model. As far as my particular needs go, no one can train them better than I can.*
 - *...make it clear that the consumer is your employer, and that you do what they want rather than what you want or what you think is best.*
2. While **training** may provide general introductory knowledge and skills, it **needs to impress upon PAs that consumers are remarkably different individuals with incredibly varied disabilities and needs.**
 - *I agree. Here at Impact, I and another person talk to classes to show that we each have different needs, and want things done in different ways. Best if PAs are experiencing firsthand knowledge as they're being trained.*

3. **PAs need to be prepared to be trained by the consumer in how the consumer wants work to be performed**, and understand that it is the PAs' job to carry out responsibilities in keeping with consumer preferences.
- *I always make it clear that if you don't want to do what I'm asking you to do, this job's not for you. Example: I want you to open a beer for me. A PA who says no [because they frown on drinking] would be fired. Same with religion. A PA who says "I do what Jesus says" was fired. You're doing something very personal. If I have you do something you don't agree with, it's nothing against you, but this is not for you.*
 - *I really truly believe that if the consumer has knowledge of their disability and they choose not to follow the diet, that's not the PA's role.*
4. **Consumers place high value on PAs' personal ethics and qualities**, more than on the skills they bring to the work. If training can support PAs in developing these qualities and understanding what is expected of them, that would be beneficial to consumers and PAs.
- *I don't care too much about your experience. If I can go to sleep knowing that you'll be here in the morning, and you don't steal from me, everything else can be learned. Those aren't really skills, those are more attitudes, I guess. I've never thought, "I wish this guy knew how to lift better," or anything like that.*

In discussion, consumers talked about the dangers they faced because some PAs misrepresent the current skills and experience they have. It's important for PAs to be very honest about those issues.

- *I always tell people, be honest with your consumer. Don't tell the consumer you know how to do something when you don't. If they say they can do something, and then arrive and don't know how to do it, it's dangerous for me.*
- *I've interviewed some people, and they say, I know how to lift dead weight, but then they drop me. You're putting me in danger. And with Daniel, with a tracheostomy, you can't mess around with that.*

Other qualities consumers discussed include:

- *Most important is to receive respect from the PA. I understand they're helping me, but it's not because I'm incompetent or lazy. I need the assistance. Being respectful is very important.*
- *Respectful toward the employer's body, and the employer's home and belongings.*
- *Trustworthy. Know how important their job is and to show up on time.*
- *Able to follow directions. Reliable.*
- *It's a high responsibility in a way that other low-paying jobs usually aren't. If you don't show up, there's a bigger consequence than for someone working at McDonald's. It's not just about a paycheck. It takes a person who can accept that kind of responsibility. I like them to respect the fact that I have preferences and I have ways of doing things that were developed through years of doing it. But I think what's important is respecting*

the employer and understanding that the employer knows best what they need, and to go with it, even if it goes against what you learned in training.

- *Patience.*
- *You have to be flexible, and you have to be open.*
- *As long as they have a good attitude about things, that's the most important thing. This is human interaction you're talking about. You have to treat people as human beings. ...we need compassion. We want care that matters.*

5. **The training program will be effective and positive if done with the CILs**, expands the reach of the training that the CILs currently offer, and if it serves to strengthen the partnership and relationships among CILs, SEIU and PAs.

6. **For training to be successful, it should involve consumers** to provide real-life experience and share the consumer's perspective (and experienced PAs as well).

- *You've probably heard people say, "Nothing about us without us." We have to be an integral part of this.*
- *I would really like SEIU to include the consumers. The PAs are coming into OUR life. You can't have one when you don't have the other.*
- *I can't imagine being effective in this without PAs having direct contact with people (consumers) you've had on this call. If you didn't, it would seem pretty hollow. It would tend to reinforce the problem of PAs not seeing consumers as employers.*
- *I think it's important to have actual people on both ends [consumer and PA], versus a trainer who has never PA'd, or a person who's never been a consumer. Because actions speak louder than words. If you've never been a PA, or you've never needed PA services, you're not believable.*

7. **Training should remain voluntary** and the program needs to avoid contributing to the development of credentials and qualifications that would limit consumers' choice in the selection of PAs.

- *Voluntary everything is good. I don't think there's any mandatory thing that anyone needs to learn. I think setting standards that are designed to increase what's perceived as professionalism—it's not of much use to me. It limits the number of people I can hire. Getting people to understand partnering in independent living is important. From my end, consumer control is ultimately important.*

I. **Hopes and expectations for the Training Program**

- *Foremost thing is that PAs understand that the consumer needs things done a certain way.*
- *More reliable PAs.*
- *PAs will provide services more safely.*

- *People who are willing and able to do the work long term. If you can get people to stay in the work for a longer time, because they find it fulfilling in ways other than financial, it'd be a great thing. Make it seem more than a nursing job, that there's more dimensions to it.*
- *If they can get better support, better pay, it's good for us and good for them. I mentioned before. Independent living, they need to know that it's a symbiotic thing.*

II. **Recommendations for the Training Program**

- a. **Should PAs Receive Training Prior to Working as a PA?** – Consumers had a range of thinking. Some thought that no prior training was necessary. Others thought that some general, basic training – that also reinforced the immense variety PAs would have to learn about from the consumers they worked for – would increase their comfort level.
- *Hard to approach in a general way; even if you say MS, I probably know 30 people who have MS, but they have 30 different ways of managing their lives. I think if you generalize, you end up misleading people. If you want to talk about a specific diagnosis, all you can tell someone is, "talk to your employer about how they manage their own situation."*
 - *I agree that there's no cookie-cutter consumer. I don't think some kind of basic training could be harmful. I think if someone has SOME training and experience, that would make me comfortable. If the training could integrate the idea that things will be different depending on where you go and who you work for, that would be great. Say that these are some guidelines, but there are more ways of doing this. If someone knew how to do something, it would give me a comfort level, would show that someone is invested in the work.*

In the discussion, we cited that many PAs suggested they should receive CPR/First Aid Training prior to working with a consumer and asked if they agreed? We heard:

- *I don't agree with that. That's a medical model. My parents didn't get training. We don't make our parents or siblings get CPR training. If I wanted that, I'd go live in a nursing home.*
- *I don't feel that it's necessarily vital for a PA to have. I don't think it's harmful if a PA knows CPR. I live with my parents, and they don't have to know CPR. I'm capable of surviving on my own at home. I want the freedoms and I wouldn't choose a PA based on his/her knowledge of CPR. I would much prefer choosing someone based on their attitudes.*
- *It wouldn't hurt, but I certainly wouldn't require it. I don't think it would be wise or fair to make it a job requirement. Requirements are troubling to me. If someone who's a college student or a single mom doesn't have that, but is great for me, and a requirement gets in the way of them working with me, that would not be good.*

b. **Training Topics Consumers Expressed Interest In**

- Universal precautions.
- It depends on what the person's disability is, and the knowledge of the specific person's disability.
- Good communications skills.
- Willingness to listen, and willing to adapt with your consumer.
- Flexibility issues
- Independent living and disability rights.
- A better understanding of the PA/Consumer relationship.
- Diabetes
- How to communicate and work with consumers who are difficult to understand at times due to their disabilities
- Orientation to variety of consumers and requirements

c. **Training Approaches**

- *For training, role plays would be good. We do that here at Access Living, and it's very helpful. You can throw ideas out there. What if this person forgets to do this? What if this person steals from you?*

III. **Thoughts on a Peer Mentor Program –**

a. **Consumers described this as a "wonderful idea."**

- *Everyone needs a mentor or someone to talk to.*
- *Beneficial to anyone who's going to be doing any kind of work to talk to someone who has firsthand knowledge. Knowing what's going to be asked of you, what's going to be required of you. If you could turn to someone and ask, how do you suggest I take care of this? That would be good.*

b. **Concern was expressed** that *"there may not be input from the person who uses the PA."* In the discussion that followed, it was suggested that consumers could be involved in the peer mentor training, and participants thought, *"That would be good. They can give their point of view."*

c. **Qualities of great peer mentors** included experience and *"That you get on. And that you're a good listener."*