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Home Care Attendant Training and Quality of Care from the Perspectives of Home Care Consumers

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EXECUTIVE SUMMARY

The term *home care* refers to the range of medical and personal care services and supports that facilitate independent living in the community. The provision of in-home services to meet needs for long-term care in the community, as an alternative to nursing home or institutional care, represents a significant shift in conceptualizing access to and delivery of this care. Previously, the concept of caregiving was interpreted as short term and rehabilitative (Talley & Crews, 2007); now, caregiving is associated to a greater extent with independence, quality of life, and in-home services. In addition, the role of the consumer has been elevated from recipient of care to that of a major decision maker in accessing and monitoring care (Dejong & Batava, 1992; Kapp, 2000; Powers, Sowers & Singer, 2006).

Given the increasingly central role of home-based caregiving in the lives of individuals with physical disabilities, we address a gap in the literature on home-based care by asking adult consumers of home care services to describe their experiences with home care, the training that their care providers have received, and their perceptions of the relationship between training and quality of care.

To conduct this study, we partnered with Philadelphia-based Liberty Resources, an organization that has a long history of service provision by and for persons with physical disabilities, and specifically with its home care agency, Home Choices. As an organization that only recently (as of January 2013) began to provide home care services *directly* to consumers, Liberty Resources Home Choices offers us a unique opportunity to explore the

relationship between care provider training and care quality, specifically for people with physical care needs.

Over the past five to six years, state-level policy changes have altered home care services policy in multiple ways, including reductions in funding available to offset the costs of training homecare providers. In this transition, Liberty Resources, its service consumers, and staff have experienced firsthand the transition from a comprehensive training model called "Building Bridges" (80 total training hours) to "Home Choices," a condensed model of pre-employment (3 hours) and in-service (minimum 2 hours per year) training.

Two factors differentiate the Building Bridges training from Home Choices and other similar training models: the intensity of the training and the involvement of care consumers in the training process. Under Building Bridges, trainings were developed and provided through the Training and Upgrading Fund of District 1199c of the National Union of Hospital and Health Care Employees (NUHHCE). The 80 hours of training brought attendants and care consumers together to learn not only the general approaches and skills involved in home-based care provision, but also the particular needs of individual consumers.

Through semi-structured interviews with 20 consumers of care and 8 attendants, we explored perceptions of care quality, homecare attendant training, and the relationship between training and quality of care. Consumers and attendants identified several elements as constitutive of "quality care." These included the following:

- Autonomy
- Mutual respect
- Access to resources both in their homes and in their communities
- Consumer-Attendant Fit
- Stability
- Attendant preparation and performance
- Attendant well-being

Our study also uncovered both consumer and attendant views on important skills and characteristics for in-home personal care providers. Notably, we received a similar, one-word answer to these questions from both consumers and attendants: *patience*. For consumers, this first P – patience – was often followed by two other Ps –*passion* and *personality*. In fact, even when asked about skills attendants should have or training topics that should be covered, consumers often brought up characteristics of the individual

attendant – a certain "personality." Lastly, consumers identified an attentiveness to the job encapsulated by the expression "on point" (i.e., focused on the work).

While autonomy, including the right to dismiss attendants, to interview attendants before agreeing to take them on, to establish standards for work quality, and to establish household rules, was highly prized by consumers, this appeared in stark contrast to consumers' *current* lack of involvement in initial training of attendants. Indeed, feedback from consumers whose attendants received training under the Building Bridges model described above, revealed a distinct preference for this training that is both hands-on and consumer-informed. Building Bridges had allowed consumers to work alongside professional trainers to teach their attendants care techniques, both generally and in reference to their specific set of needs and preferences.

Perhaps the most compelling contrast between consumers and attendants trained under Building Bridges and those trained more recently was the former's strong recollection of training content and ability to connect the training to a current skill set. By contrast, consumers who had begun to receive services more recently knew very little about the training that had been received by their attendants. Interview evidence suggests that, while even the 3-hour training provides attendants with some useful general knowledge with which to begin, attendants lack condition-specific knowledge, as well as hands-on knowledge. In some cases, this leads to some in-home trial-and-error that may, in turn, contribute to failed consumer-attendant connections; frustration, anxiety, and shame on the part of consumers and attendants; and even a risk to consumers' physical well-being.

Homecare attendants provide services that allow people to live in their own homes and that give respite to familial care providers. The work is intimate and often prolonged. While brief, topical trainings do play a role in preparing homecare attendants, the gap between consumer and new attendant expectations seems best addressed through consumer-informed and/or consumer-facilitated training in partnership with professional trainers.

INTRODUCTION AND BACKGROUND

The concept of *care work* (England, 2005) has emerged from multiple disciplines as both increased longevity and advancements in medical care and health technology have resulted in growth in numbers of older adults and individuals with disabilities (Talley & Crews, 2007). The term *home care* refers to the range of medical and personal care services and supports that facilitate independent living in the community. The distinction between levels of care is generally established by agency providers who monitor care in accordance with funding and licensing regulations (Kapp, 2000).

Over the past 40 years, older adults and individuals with disabilities have successfully advocated for a greater array of choices in care services, opening up opportunities for individuals to remain in their own homes or other home settings while still accessing needed medical and personal care. Consequently, recent reports by the Bureau of Labor Statistics (2012) related to community- and home-based personal care have predicted personal care aides to be the fastest growing occupation between 2010 and 2020, yet the demand for these services is also expected to double, creating a significant shortage of workers (Butler, Brennan-Ing, Wardamasky, & Ashley, 2014). Even as demand for home care attendants grows, there is substantial variation at every level – state, locale, and agency – pertaining to regulation or standardization of attendant preparation and training (Powers et al., 2006).

The Institute of Medicine (2008) has approached the projected shortage of home care workers in its assessment of current health care needs and analysis of the contemporary health care workforce. This discussion has unveiled patterns of low pay, poor working conditions, high levels of job injury and job stress, limited training, and concerns about the quality of long-term supportive care. One promising result of this committee's work has been an increased awareness and emphasis on the need for developing comprehensive, coordinated, and efficient models of care that reflect an increase in size and skill to respond to predicted demand for services. Most importantly, this approach must include all levels of caregiving, especially home and community-based supports.

The provision of in-home services to meet needs for *long-term* care in the community, as an alternative to nursing home or institutional care, represents a significant shift in conceptualizing access to and delivery of this care. Long-term support services are focused on caregiving to facilitate *independence* as opposed to medical care related to the illness that caused *dependence* (Bishop, 2004). Previously, the concept of caregiving was interpreted as short term and rehabilitative (Talley & Crews, 2007); however, as the result of reframing

caregiving in the context of community-based care, caregiving is now associated to a greater extent with independence, quality of life, and in-home services. In addition, the role of the consumer has been elevated from recipient of care to that of a major decision maker in accessing and monitoring care (Dejong & Batava, 1992; Kapp, 2000; Powers, Sowers & Singer, 2006).

To date, research on home care services has focused primarily on typologies of care (Fine, 2012; Moroney & Dokecki, 1998), caregiver stress and burden (Duffy, 2005; England, 2005; Schulz, Beach, Cook, Martire, Tomlinson & Monin, 2012), the concept of consumer-directed care (Powers, Sowers & Singer, 2006; Talley & Crews, 2007), and caregivers' access to training (NAC, 2009; Stone & Wiener, 2001). Absent from this literature are the voices of consumers articulating their views of quality of care, caregiver training, and the link between the two. We address this gap by asking adult consumers of home care services to describe their experiences with home care, the training that their care providers have received, and their perceptions of the relationship between training and quality of care.

To conduct this study, we partnered with Liberty Resources, an organization that has a long history of service provision by and for persons with physical disabilities, and specifically with its home care agency, Home Choices. While the bulk of its home care services are provided in Philadelphia, its service reach has expanded to include counties across Pennsylvania.

As an organization that only recently (as of January 2013) begun to provide home care services *directly* to consumers, Liberty Resources Home Choices offers us a unique opportunity to explore the relationship between care provider training and care quality, specifically for people with physical care needs. The context in which Liberty Resources has moved from being a fiscal intermediary in a "consumer-as-employer" staffing structure to a direct provider of care is also distinct. Its home state, Pennsylvania, has altered home care services policy in multiple ways, including reductions in funding available to offset the costs of training homecare providers. In this transition, Liberty Resources, its service consumers, and staff have experienced firsthand the transition from a comprehensive training model called "Building Bridges" (80 total training hours) to "Home Choices," a condensed model of pre-employment (3 hours) and in-service (minimum 2 hours per year) training.

Two factors differentiate the Building Bridges training from Home Choices and other similar training models: the intensity of the training and the involvement of care consumers in the training process. Under Building Bridges, trainings were developed and provided through the Training and Upgrading Fund of District 1199c of the National Union of Hospital and

Health Care Employees (NUHHCE). The 80 hours of training brought attendants and care consumers together to learn not only the general approaches and skills involved in home-based care provision, but also the particular needs of individual consumers.

As a result of state-level policy change, the funding used to provide home care attendant training was eliminated, resulting in a substantial reduction in capacity to provide training to newly hired attendants. While the organization continues to offer both initial and in-service training to attendants, start-up training is limited to a single day and no longer involves consumers directly.

Through semi-structured interviews with 20 consumers of care and 8 attendants,[1] we explored perception of care quality, homecare attendant training, and the relationship between training and quality of care. We intentionally sought out respondents who had received services under the Building Bridges training model and respondents who had begun receiving services only recently. The home care service provision that is the focus of this research can be categorized as non-medical attendant care which includes personal care activities to support persons with functional limitations to live independently in the community.

SAMPLE AND DATA COLLECTION METHODS

The research reported herein was approved by the Institutional Review Board (IRB) of Rutgers, the State University of New Jersey, in April 2014. Throughout the summer of 2014, Liberty Resources Home Choices distributed letters inviting consumers and attendants to participate in interviews lasting approximately 30 to 60 minutes. Potential participants were told that they would be asked about their experiences receiving or providing home-based care and their opinions regarding the relationship between attendant training and quality of care. *Attendants* interested in participating in the study contacted the Center for Women and Work (CWW) at Rutgers University directly. *Consumers* interested in participating in the study contacted CWW either directly or through a Liberty contact. CWW then scheduled interviews with consumers and attendants in their homes if possible or by phone if they preferred.

Prior to each interview, consumers and attendants signed detailed consent forms, with separate forms providing consent for the interview itself and for audio-recording of the

[1] Both "consumer" and "attendant" are identifiers used by our partner agency.

interview. Each participant received $25 prior to the start of the interview, delivered in person if the interview took place in the home and via mail if the interview took place via phone.

We conducted semi-structured interviews with 20 homecare consumers and 8 attendants between August 19, 2014, and September 16, 2014. Sixteen of the 20 consumer interviews, and 3 of the 8 attendant interviews, took place in the homes of the interviewees. Interviews ranged in duration from 15 to 75 minutes. Interviews were transcribed and analyzed for themes related to service quality, training content, and training impact, with coding carried out by two coders, one of whom was also the primary interviewer for every interview.

Our sample included 12 female and 8 male consumers and 8 female attendants. The length of time for which those interviewed had received homecare services ranged from 3 months to over 10 years.

RESULTS

What Elements Constitute Quality Care?

***Autonomy*:** One of the most prominent themes emerging from the interviews was that of autonomy or independence. Consumers of care brought up autonomy as something they liked or valued about their current experience when autonomy was present for them and as something that could be going better when they felt autonomy was lacking for them. Some consumers saw home-based attendant care in a very immediate and ongoing way as an alternative to the isolation and dependence that they associated with nursing home care. A few even spoke of asking home care agencies to help them advocate for release from institutional care or from temporary hospitalizations. Consumers described how home care services have given them some control over their living conditions, making it possible for them to live with or near family members and friends and to engage with their communities.

In describing one of the first consumers with whom she worked, an attendant observed,

> *She was in a nursing home for a couple of years, and when they just come home from the nursing home, they are so afraid. So afraid…. People just don't realize what it means to those people who can get out of those nursing homes and have somebody come in and help them every day.*

One young adult consumer described her concerns for the future, linking them to her desire to maintain her independence:

> *For me, because I think it's important, for me- my independence. Because my biggest fear is ending up in a nursing home. So, it is important to have that choice to stay in my home. It always scares me with all the budget stuff going on that could be taken away. That it is not guaranteed. That worries me a lot and just to have that choice to who I hire. I don't want that to ever be taken away from me. As we expressed, we have had those issues of people we don't know coming in here and that scares me- not having that choice of who to work for me because they are coming into my home. I fear that with some of the things that go on and people who are elected into office don't care about that or just don't even take it into consideration. That they view something one way because they're not living it, and it's so important when you're living it. It is very important who I choose to help me to remain independent so I don't end up in a nursing home.*

Consumers described (and almost uniformly celebrated) having direct authority over their attendants in a number of ways, including the right to dismiss attendants they found unsuitable, the right to interview attendants before agreeing to take them on, the right to establish standards for work quality, and the right to establish household rules (e.g., break times, use of cell phones). A few consumers shared dissatisfaction with the expectation that they contact the agency first if a scheduled attendant does not show up, and some shared that they are either fighting this policy or that they actively ignore it, calling in reliable attendants in the case of "no-shows" and then working with Liberty to adjust the schedule accordingly. As one consumer shared,

> *…the reason I left the agency I was with [before Liberty] is because they didn't provide me with the flexibility that I felt that I needed. Just because they were sending me,… like Liberty will send me out an attendant but then they are very good with me about when I may need to switch up somebody. The other agency wasn't.*

A few consumers expressed appreciation both for the elements of service over which they had control and for the elements of service that they could leave in Liberty's hands. For example, one man shared,

> *What I like about it is that I can manage the schedule but I don't have to do any of the paperwork, and - say if I get tired of an attendant and have to get rid of them - let Liberty do it. I'm not going to do that.*

Our interviews revealed a number of negative experiences that consumers had had with attendants, including concerns with job performance, falsifying reports of hours worked, theft, and direct requests to consumers for higher pay or more hours. However, perhaps one of the most compelling pieces of evidence for the theme of autonomy was the extent to which consumers felt empowered to dismiss attendants in these situations. In each case that consumers reported problems with attendants, they also reported that Liberty supported termination decisions and found replacement attendants promptly.

For the most part, the consumers interviewed reported that they were managing challenges well, that the agency was responsive, and that they believed they had the power to improve services.

***Respect*:** Both consumers *and attendants* associated quality of caregiving with attendant behaviors and attitudes that demonstrate that the home belongs to the consumer, not to the attendant. The word, *respect*, was threaded throughout interviews with both consumers and attendants. Quality attendants were described as respecting consumers' independence and ownership of both their time and their space.

One attendant noted that she has learned that, "You have to do things the way they [consumers] want you to do them. You can suggest things, but I try to do exactly what they tell me to do." She described this principle as important both to the quality of her work and to the quality of the work of home care in general.

One consumer connected a lack of respect at an individual level to a more general lack of respect for people with disabilities:

> *…some people can come in and really treat you as if… some people (not all people) can have a preconceived notion that people with physical disabilities either have mental retardation of some sort - so you can get someone to come in who really treats you like that and you are like- 'no.'*

What was again striking, however, was the consistency with which consumers and attendants expressed confidence that, if they were dissatisfied with the level of mutual

respect in a consumer-attendant match, they could either change the situation for the better or leave it entirely. As one consumer shared,

> *With family. You gotta put them in their place. I want you to be my attendant, but we're not just gonna sit there and … talk for 8 hours. You are going to do what I tell you to do or you will be fired.*

Access: Consumers shared that they valued having access to resources and experiences associated both with their own homes and with their surrounding communities. As such, they described quality caregiving as care that provides safety and protection, as well as opportunities for shared learning experiences. While consumers emphasized wanting and needing attendants to work autonomously, be self-motivated, and follow consumers' preferences for home and personal care, many also valued working collaboratively with their attendants.

One consumer explained that her attendant had showed her how to make crafts and had taught her to sew, even bringing a sewing machine to the consumer's home when the consumer expressed a desire to learn. Now, this consumer is able to create and sew items to give as gifts. An attendant described the reciprocity that exists between her and the consumer with whom she works:

> *I actually can cook but she likes to cook the way she like to cook. So we get together and we cook the way she want to cook. She enjoy that. No matter how she is, she enjoys that. I am glad that I can bring that out of her.*

Consumers and attendants both spoke positively about shared experiences outside of the home. Attendants accompanied consumers regularly on shopping trips and doctors' appointments, and brought consumers outside to interact with neighbors and other community members. Being able to access stores and thus products of their own choosing was highly valued by many consumers. One consumer with a particularly complex array of medical concerns described her attendant as an essential and trusted repository of information:

> *She goes to the doctor with me and stuff like that and that helps because I fall asleep and need to know what the doctor says. Like last week when I went to the doctor, she said I got your prescriptions together like we talked about- I would say- 'What did we talk about?'*

Relationship Fit: While acknowledging that relationship fit is not an essential characteristic of home-based attendant care, several consumers and attendants identified relationship quality as something they valued and liked about their current arrangements. One consumer described her attendant as the "perfect person," in part because of her punctuality and dependability and in part because of her personality. This consumer noted that she had been told by various service agencies that attendants were not there to be consumers' friends but concluded, "You can't stop the friendship from happening; the bond comes in."

Consumers described instances of celebrating achievements, such as improved mobility or equipment upgrades, with their attendants.

A few consumers identified their feelings of concern for their attendants as obstacles to reporting deficits in work quality, punctuality, or attendance. This was particularly true when the attendant in question was a family member. In one case, a consumer shared that one of his service providers had advised him to be less "familiar" and "disclosing" with his attendants and that this had helped him to better manage his care. Overall, however, consumers who reported having had challenges of any sort with attendants were united in sharing that, once they had decided to take action, they could turn their concerns over to Liberty and Liberty would promptly find a replacement.

Several home care attendants also spoke of providing company and conversation as aspects of their work. However, they made clear that this was something negotiated, either explicitly or implicitly, with each service consumer. They distinguished between consumers who preferred attendants to be task-oriented throughout their scheduled hours and consumers who enjoyed conversing while the attendant worked or who liked to use attendant hours to accomplish shopping needs and take other community trips.

One attendant, who had provided home care services for many years, described her views of her work as follows:

> *I say that I don't want to get close but how can you work with somebody and not be close and become family? Especially every time you turn around- [they may be] in the hospital. Then [they're] barely eating. That does a toll to my heart every once in a while. My heart bleeds- I play that 'tough tony' role, but I bleed just like everybody else. When you are hurting, I am hurting too.*

Stability: Stability of care provision – care that is continuous, consistent, and timely – was identified as a key element of care quality, made most apparent when it was lacking.

Consumers shared several stability-related concerns about their attendants, past and present, including turnover, no-shows, and punctuality. Several discussed their concerns about attendant turnover, including one who shared,

> *To be really honest, I really don't like so much change. I don't like it. There's too many different personalities. There are too many different spirits. Different people have different spirits. You know? I don't like really dealing with that all the time. Because what's on you can either drain me or pick me up.*

Another consumer noted,

> *I don't like getting to know different ones. It really throws me off, you know? Then I need to show them the ropes- what I like and what I don't like.*

As noted in the discussion of the *Relationship Fit* theme, consumer-attendant relationships that are "working" are often grounded in stability of care provision:

> *So, she does what I want her to do when I want her to do it and she doesn't ask too many questions. We do socialize and have a good time when she is here but she goes home when she is supposed to and she comes when she is supposed to. And that is the way I want it.*

Attendant interviews offered some insight into a few of the "supply side" factors that may be getting in the way of stable caregiving. Several of the attendants newer to Liberty shared that, while they were building up their work hours, they often took on "split schedules," seeing consumers in different parts of the city, with gaps of time between jobs. Because many attendants rely on public transportation to get from site to site, and many have family caregiving responsibilities of their own (e.g., care of young children), they juggle many scheduling uncertainties throughout the day. These uncertainties may become obstacles to punctuality and attendance and, ultimately, may increase attendant turnover.

Preparation and Performance: All 20 consumers interviewed identified elements of preparation and/or performance as valued qualities of the care they received. As one consumer noted,

> *Every aide that I have had, they come to me first and they ask what do you need us to do? And I point out the spot. And they go just right to work.*

Included in this area was a general appreciation of work ethic, as well as concerns about the frequency and timing of breaks and conflicting understandings of attendant responsibilities (e.g., standards of housekeeping). Most consumers had distinct preferences for cleaning supplies, approaches to housekeeping, and housekeeping priorities and, in a few cases, these approaches or priorities conflicted with those of their attendants. Some consumers spoke with great humor about finding "common ground" with their attendants; for others, the gulf between the consumer-driven requirements of the job and the attendant's work product was insurmountable and the attendant was dismissed. It is important to note that, in light of the severity of the medical challenges faced by most consumers, aspects of household maintenance, including meal preparation, dusting/vacuuming, and maintenance of orderly spaces (e.g., essential supplies placed in the reach of consumers; clear paths for consumers to walk or use wheelchairs) are not mere preferences, but rather essentials:

> *Yes, they have to change my tubing. They have to change the tie that goes around my 'trach.' They have to clean my equipment and, when my supplies come in, they have put up all my supplies. It's a lot that they have to do to help me.*

Several consumers drew a contrast between attendants with and without established work patterns. One consumer described an attendant who was so punctual, consistent, and hard-working that the consumer was willing to work with her until she acquired a missing skill: the ability to cook:

> *I have had one girl who came and told me point blank - she said she didn't know how to cook. And I thought, 'Oh Lord.' But it worked out. It worked out for both of us. She was young so you can expect that out of her. She's just a young person just learning so I didn't hold that against her.*

Attendant Well-being: Consumers were not asked about attendant well-being, nor were they asked about details such as salaries or benefits, but several expressed interest in their attendants' lives beyond the work days. A few volunteered that they would like attendants to have better access to benefits, including higher pay, overtime when they work "past that clock," and paid time off. Three consumers quoted below shared their concerns about attendant well-being and linked these concerns to quality of care:

> *They're [Attendants are] human too and they have to live on the outside; they have an outside life as well as they do coming in. So, I have to remember that. You have to consider that. They've got family too. They go through everything we do.*

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As for me, I found that you have to manage your care to make it work for you, and also make it work for your attendants because they have lives too. And I think that sometimes, from what my attendants tell me, and I have had a lot of attendants both Liberty when I started and for the other agency… And the younger ones -the biggest issue they talked about was lack of respect from the agency sometimes and from other consumers.

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…I admire those aides who comes out for 2 or 2 ½ hours but by the time they get there and they spend on their coffee, and spend whatever, they have ate up the money that they supposedly make…. … I also say, for me, I think this work should start out at $15/ hour. Just from a human perspective. And raising families and raising kids and trans [transportation] pass costs- at $82/month –if you don't have a transpass, tokens cost at $18/week. $18!

When we asked attendants to tell us about "some things that [they] think would help to make [their] job easier or better," areas identified included greater access to training, more work hours, consistent and/or consecutive shifts, increased wages, and access to benefits such as health insurance. One attendant, who was animated in describing her enjoyment of her job, shared,

So. Because I don't have it [health insurance], the emergency room is always available. I don't know, it wears you out. I guess because the bills keep coming and I take them to welfare but they deny me and tell me I make too much money. I just suck it up and keep moving.

What Characterizes a "Good Attendant?"

In an effort to identify both consumer and attendant views on important skills and characteristics for in-home personal care providers, we asked similar questions of consumers and attendants. Specifically, we asked consumers the following question: "What are some things that you think are important for anyone providing care in another person's home to know?" We asked attendants the following question: "What are some things you have learned in the course of providing care for other people?"

Notably, we received a similar, one-word answer to these questions from both consumers and attendants: *patience*. One consumer elaborated, stating that attendants should,

> *Be able to tolerate and be able to cope with the fact that you may be dealing with someone who has been sick for a long time; they might mood swing on you at any moment because of their illness and it has nothing to do with you personally. So, they [attendants] should be taught in some degree about how to handle mood swings and not to reflect on themselves individually. Not to take it personally.*

For consumers, this first P – patience – was often followed by two other Ps –*passion* and *personality*. As one consumer noted,

> *They [home care attendants] have to have patience in the first place; you have to have a certain passion and compassion. If you go and do this work and what I see happen is…Do you know why people don't stay in this job? Because they* lose passion. *Passion is what keeps you in any job. If you lose the passion…Particularly, in this job. And I can understand why you would lose the passion. Because it is a rough field. A rough field.*

In fact, even when asked about skills attendants should have or training topics that should be covered, consumers often brought up characteristics of the individual attendant – a certain "personality."

> *Like, supposed to be caring. You have to want to love the job in order to do it. Even to my neighbor or someone outside. When we go out, I expect you to be supportive, not sympathetic but to be loving and kind and to help with care.*

In addition to the "three Ps" of patience, passion, and personality, consumers identified an attentiveness to the job encapsulated by the expression "on point" (i.e., focused on the work). From the perspective of individual-as-employer, attendants are expected to be "on point" because this is what the job requires; being "on point" is a signifier of quality service. From the perspective of individual-as-service-consumer, attendants must be "on point," or the consequences for medically vulnerable individuals may be serious and even devastating. As one consumer noted,

> *…you might make sure that you know how to assist them with the wheelchair. If they fall, you got to know what to do- what you're supposed to do and be 'on point' with*

> *that. If they choke, you need to know how to help the person; you can't wait for the phone call. You could call but you got to start doing some pumping or something.*

Another consumer, relatively new to Liberty's services and with an active seizure disorder, noted that her home care attendants need to be able to recognize early signs of a seizure, to operate her air filter/purifier, and to act quickly and capably in the case of an emergency. She noted that, while she tries to show new attendants everything, it would really be more useful if they knew more when they came. She observed, "If they don't know, I'm in trouble. So more medical background would be great."

Other things that consumers believed their attendants needed to know included the following: CPR; wound and rash care; signs of "different ailments;" emergency procedures; transfers; use of a hoyer lift; how to put a person in a shower of bathtub; dietary needs; the importance of keeping spaces clear and uncluttered; preserving consumer hygiene; cooking/cleaning; signs of abuse, neglect, or dangerous living situations; privacy and sensitivity; listening skills; and how to connect other prospective consumers with services.

In What Ways is Attendant Training Linked to Care Quality?

Contrast between Past and Present Training Models: We interviewed five consumers and one attendant who had been part of the 80-hour Building Bridges training program conducted through the Training and Upgrading Fund of District 1199c of NUHHCE, as well as a second attendant who received training in the transitional period between Building Bridges and full implementation of the current brief training model. They were united both in endorsing the training and in comparing the current training model unfavorably. As one consumer noted,

> *With Liberty and the other agency, I could tell the quality by how the workers were trained. I guess that is why I brought two of the workers back because they were trained 7 or 8 years ago.*

One attendant described her experience with the earlier training model, the very early stages of Building Bridges, as follows:

> *The training they gave me was unbelievable. [Trainer's name] is a registered nurse. She gave me one-on-one training and she taught me everything I know. Everything-one-on-one: the feeding tube, how to pack a sore. She just taught me – how to suction a trach. I just know that [she] taught me everything. It is just like once you learn it, you*

> *never forget it…. She did an excellent job and I loved it because it was a one on one and she came back… She must have come back and said, now show me what I taught you. I was like- pow, pow, pow, pow. It was just something in my mind that would never leave me.*

Although our questions asked generally about training, rather than specifically about Building Bridges, consumers and attendants volunteered information specific to the program. One consumer with an upbeat demeanor and significant mobility and speech difficulties became quite animated when she talked about going to Liberty and getting trained with "1199c." She shared that she had attended multiple training sessions at Liberty with new attendants and that these trainings had taught her attendants "not to be afraid." Building Bridges had allowed her to work alongside professional trainers to teach her attendants care techniques, both generally and in reference to her specific set of needs and preferences. With the guidance of trainers, attendants practiced skills in areas such as feeding and transferring. As this particular interviewee noted, during training "[I can tell you] if you hurt me so I will let you know what needs to be done."

Another consumer shared that, a number of years ago, she had attended Building Bridges training sessions with her new attendant and that, together, they had learned CPR and how to treat pressure wounds, among a number of other things. She said that they had both received a certificate at the conclusion of the training, that they both had had fun, and that she had walked away with knowledge to complement the knowledge acquired by her attendant.

As noted above, we interviewed one attendant who received training during the transition from the Building Bridges training model to the current, brief training model used by Home Choices. She recalled a week of training, that included topics such as how to interact with consumers, what it means to be properly presentable on the job, how to use lifts (including hands-on practice with other training attendees), ways to reduce agitation for consumers with dementia, and policies specific to Liberty, such as not handling consumers' money and using gloves while working with consumers. She expressed general satisfaction with the training but noted that, particularly given the importance of hands-on training and differences in learning style and pace, she would personally recommend a training period of two or more weeks.

Perhaps the most compelling contrast between consumers and attendants trained under Building Bridges and those trained more recently was the former's strong recollection of training content and ability to connect the training to a current skill set, as evidenced above.

By contrast, consumers who had begun to receive services more recently knew very little about the training that had been received by their attendants. Those who seemed to know anything at all about the training described it as a "video" or series of videos. The two quotes below are illustrative:

> *Well, before they're able to become a home health aide, they have a 3-hour orientation. They have to get their background checks. All of them have to have a background check.*

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> *I don't really know, personally. I just know what they tell me. They tell me that they watched a movie. They did a couple…That's all they tell me… they tell me they watched a movie… what else they do?... Hold on. I don't really remember.*

Another consumer shared that he knows that Liberty does show a video, focusing on things like "courtesy and etiquette," to new attendants, but he is not sure whether that is sufficient and whether it is really making a difference.

Attendants also described a video or videos of roughly three hours, focusing primarily on how to talk to homecare consumers, hygiene, and emergency protocols. Attendants identified two elements of the training as particularly helpful: how to enter a consumer's home respectfully (including how to follow a consumer's lead in organizing the day's work) and what to do in case of an emergency. Experienced attendants (even if the past experience consisted only of caring for a relative) tended to view the brief training as "good" but not essential. As one attendant noted,

> *When you go in these companies and they show you these films, it helps you deal with a lot of situations that might come up…. They don't give you a lot of hands-on but what they show you is helpful if certain situations come up. …. . Like once you leave the facility after you see the training you might not think about it but it comes back to me as certain situations arise so you say- ok. I can say it can be helpful. I don't like to sit and watch stuff like that but it comes back to me when certain situations arise. So I can say it was helpful.*

Another attendant observed that it seemed like "they were showing the same thing over and over again." She expressed an interest in having more extensive or more diverse training.
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As both consumers and attendants responded to our questions about attendant training, two primary themes emerged: one pertained to the lack of individual preparation attendants have before entering someone's home and the other was the value of hands-on and consumer-informed training in general.

Lack of Individual Preparation: Interview evidence suggests that even the 3-hour training provides attendants with some useful general knowledge with which to begin. However, attendants lack condition-specific knowledge, as well as hands-on knowledge, and, as predicted by one consumer below, this may lead to some in-home trial-and-error:

> *Well, I think they should know the person's condition so they're trained in what the person needs help with. Get training. Know the person's disability and determine if that's good for you or not. Some people can't work certain stuff. They say they can until they get into it but they realize they can't and then you have to look for another worker and all that.*

In one of the interviews, the consumer requested that her attendant remain during the interview. In this particular case, the attendant had been on the job for only three months. The consumer shared that when her attendant had first arrived at her home, the attendant had not been at all prepared for her particular and extensive set of needs. While the consumer relayed this account, her attendant nodded animatedly. Initially overwhelmed because she had had no prior knowledge or information about the consumer's multiple care needs, this attendant performed her first transfer from bed to chair, alone with the consumer. In this case, the consumer, who had experienced the past Building Bridges training model, expressed confidence in her ability to train her own attendants, even when they come unprepared.

Another consumer noted that, most of the time, when attendants come to her for the first time, they have not been told ahead of time about her condition. In fact, she could not recall a single time that an attendant came out and actually knew something about her before they got there. And then she quipped, "Sometimes they panic and run away."

While several attendants had experience caring informally for a parent, grandparent, or other family member, consumers noted that this was qualitatively different:

> *…when a nurse's aide comes into employment, they should have more skill other than working with their mother and father. Because you're dealing with somebody totally different than your mother and father. It's a whole new ballgame altogether. So, they*

> *need to be taught that family members - taking care of family members - and taking care of an individual who has been sick for a long time is two different worlds. And you're going to feel a different way.*

Two consumers provided specific recommendations for changes to address the uncertainty of the "first day:"

> *Also, I think that, and I haven't seen this with too many agencies, I think that sometimes the office staff (the schedulers) should get to know who they are sending out a little bit more to the client. I think, for Liberty, what they need to do, they need to also have to have where they come out and they do an interview with the attendant and the consumer. Sometimes, the staff in the office need to come out and see what the aide has to go through.*

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> *And I think it should be more for an aide coming into the home with a little card and they could say, this is what the consumer needs because a lot of times the aide comes in just blank. If you don't have a family member there or you can't explain what you need the aide to do, it could be the blind leaving the blind. But in most cases, it's not but I think the attendant should know what they're walking into. I think they should at least give them that much respect- even it is just a brief synopsis that says – you know.*

Hands-on and Consumer-informed Training: The majority of, though certainly not all, consumers wanted the opportunity to train their attendants. One connected the authority to hire with the authority to train, arguing that the two should be linked. While some identified areas in which their attendant would benefit from specific training, the predominant message was that the best training must come from the consumer.

> *I would rather have people come and see me at home, and this is a way that they can get a real feel of the house as to how they could help or maybe what they could be doing that could not be helpful.*

Attendants trained over the past five years had no direct experience of alternative training models, nor did they know that Liberty consumers and attendants had ever had access to a different model. However, a few identified the lack of hands-on training as a possible deficit. One shared, "I just believe that, hands-on experience is good. You got to do it the consumer way because that is the right way. Their way is the right way."
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Another observed, "My attention span is not the greatest for books, but if you show me how to do something, I am the hands-on [person]."

Only consumers can tell the attendant when they are in pain or what signs indicate distress. Waiting to discover this until the "first day" – when consumers and attendants are first meeting and are typically alone – may contribute to failed consumer-attendant connections; frustration, anxiety, and shame on the part of consumers and attendants; and even a risk to consumers' physical well-being.

CONCLUSION

To date, research on home care services has focused on the training and self-care needs of both family and non-family caregivers, as well as on profiles and descriptions of approaches to care, including consumer-directed care (Duffy, 2005; England, 2005; Fine, 2012; Moroney & Dokecki, 1998; NAC, 2009; Powers, Sowers & Singer, 2006; Schulz, Beach, Cook, Martire, Tomlinson & Monin, 2012; Stone & Wiener, 2001; Talley & Crews, 2007). We add to the existing literature by asking adult consumers of home care services to describe their experiences with home care, the training that their care providers have received, and their perceptions of the relationship between training and quality of care.

Interviewing consumers of home care services from Liberty Resources Home Choices offers us a unique opportunity to explore the relationship between care provider training and care quality, specifically for people with physical care needs. Over the past five to six years, state-level policy changes have altered home care services policy in multiple ways, including reductions in funding available to offset the costs of training homecare providers. In this transition, Liberty Resources, its service consumers, and staff have experienced firsthand the transition from a comprehensive training model called "Building Bridges" (80 total training hours) to "Home Choices," a condensed model of pre-employment (3 hours) and in-service (minimum 2 hours per year) training.

Two factors differentiate the Building Bridges training from Home Choices and other similar training models: the intensity of the training and the involvement of care consumers in the training process. Under Building Bridges, trainings were developed and provided through the Training and Upgrading Fund of District 1199c of the National Union of Hospital and Health Care Employees (NUHHCE). The 80 hours of training brought attendants and care

consumers together to learn not only the general approaches and skills involved in home-based care provision, but also the particular needs of individual consumers.

Through semi-structured interviews with 20 consumers of care and 8 attendants, we explored perceptions of care quality, homecare attendant training, and the relationship between training and quality of care. Consumers and attendants identified several elements as constitutive of "quality care." These included the following:

- Autonomy
- Mutual respect
- Access to resources both in their homes and in their communities
- Consumer-Attendant Fit
- Stability
- Attendant preparation and performance
- Attendant well-being

Our study also uncovered both consumer and attendant views on important skills and characteristics for in-home personal care providers. Notably, we received a similar, one-word answer to these questions from both consumers and attendants: *patience*. For consumers, this first P – patience – was often followed by two other Ps –*passion* and *personality*. In fact, even when asked about skills attendants should have or training topics that should be covered, consumers often brought up characteristics of the individual attendant – a certain "personality." Lastly, consumers identified an attentiveness to the job encapsulated by the expression "on point" (i.e., focused on the work).

While autonomy, including the right to dismiss attendants, to interview attendants before agreeing to take them on, to establish standards for work quality, and to establish household rules, was highly prized by consumers, this appeared in stark contrast to consumers' *current* lack of involvement in initial training of attendants. Indeed, feedback from consumers whose attendants received training under the Building Bridges model described above, revealed a distinct preference for this training that is both hands-on and consumer-informed. Building Bridges had allowed consumers to work alongside professional trainers to teach their attendants care techniques, both generally and in reference to their specific set of needs and preferences.

Perhaps the most compelling contrast between consumers and attendants trained under Building Bridges and those trained more recently was the former's strong recollection of training content and ability to connect the training to a current skill set. By contrast,

consumers who had begun to receive services more recently knew very little about the training that had been received by their attendants. Interview evidence suggests that, while even the 3-hour training provides attendants with some useful general knowledge with which to begin, attendants lack condition-specific knowledge, as well as hands-on knowledge. In some cases, this leads to some in-home trial-and-error that may, in turn, contribute to failed consumer-attendant connections; frustration, anxiety, and shame on the part of consumers and attendants; and even a risk to consumers' physical well-being.

Homecare attendants provide services that allow people to live in their own homes and that give respite to familial care providers. The work is intimate and often prolonged. While brief, topical trainings do play a role in preparing homecare attendants, the gap between consumer and new attendant expectations seems best addressed through consumer-informed and/or consumer-facilitated training in partnership with professional trainers.

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