



University of Connecticut Health Center

October 2007

Medicaid Infrastructure Grant Needs Assessment:

Personal Care Assistance

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Acknowledgements

We gratefully acknowledge the help of all the volunteers who willingly gave their time and shared their thoughts and experiences with us. This includes people with disabilities, employers, providers, and others who participated in a focus group or completed an interview or telephone survey for us. Without all of your voices, this report would not be possible.

We are also grateful for the direction and support provided by Amy Porter, Dawn Lambert, and other members from the Connecticut Bureau of Rehabilitation Services, Department of Social Services, as well as the members of Connecticut's Medicaid Infrastructure Grant Steering Committee.

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I. Introduction

This study is part of a larger study funded by the Centers for Medicare and Medicaid Services (CMS): the Medicaid Infrastructure Grant (MIG). MIG is designed to support the competitive employment of people with disabilities. Awarded to the Connect to Work Center at the Bureau of Rehabilitation Services, Connecticut Department of Social Services, the grant is intended to facilitate enhancements to the state Medicaid program and services, to promote linkages between Medicaid and other employment-related service agencies, and to develop a comprehensive system of employment supports for people with disabilities.

Beginning in January, 2006, the Connect to Work Center contracted with the University of Connecticut Health Center (UCHC) to conduct a statewide needs assessment for the MIG. With direct guidance from the MIG Steering Committee, the research team developed a multi-pronged approach to contact people with disabilities, employers, and service providers throughout Connecticut to assess their experiences, attitudes, and observations about employment for persons with disabilities. Connecticut participants in the Medicaid Waiver programs were evaluated regarding employment, future employment plans, use of personal assistant services, and self-directed care.

The needs assessment included seven distinct research activities. This approach was used to gather information from multiple sources and stakeholders.

- 1) Conducted an extensive search of relevant literature. This step guided the development of the methods of collecting data and the data collection instruments.
- 2) Connecticut Census and Department of Labor data were examined to set the context.
- 3) Potential partners were sought out from existing state councils, work force development boards, and other entities.
- 4) People with disabilities completed a survey by mail, telephone, or in-person. The survey included both quantitative, forced-choice questions and qualitative, open-ended questions about their experiences, expectations and needs regarding work and personal assistance.
- 5) Key informant interviews and focus groups with stakeholders were conducted. People with disabilities, family members, employers, and service providers participated in group discussions and one-on-one interviews that utilized a guiding set of open-ended questions addressing the key areas of concern.
- 6) A mailed survey went out to employer members of four regional Chambers of Commerce to gather their input.
- 7) The employment processes of four key state agencies were explored and mapped to identify strengths, weaknesses, overlap, and opportunities for collaboration and streamlining in the existing state system.

This report focuses on those people who have experience with personal care assistants (PCAs) and examines contributing factors to the relatively low numbers of people using PCA support services in Connecticut. For a comprehensive overview of all seven components of the needs assessment, please refer to the August 2006 Medicaid Infrastructure Grant Needs Assessment: Final Report. A copy of this report is accessible at: <http://www.brs.state.ct.us/StrategicEmployment.htm>.

II. Literature Review

Increasing numbers of people with disabilities are embracing consumer-directed care that uses Medicaid as the main funding source and are receiving personal care services in their own home (Seavey & Salter, 2006). Personal Care Assistance Services (PCA), also known as Personal Assistance Services (PAS), are contrasted with the “medical model,” an approach that underscores professional decision-making and supervision (Doty, 2004). PCA are part of the current paraprofessional long term care workforce forming the centerpiece of the recognized long term care system that emphasizes independence and encourages autonomous living (Caro, 2001; Clinco, 1995; Dautel & Frieden, 1999; Stone & Wiener, 2001). PCA provide a range of services including essential hands-on care and support to millions of adult individuals with chronic disabilities who may or may not be employed (Doty, Eustis, & Lindsay, 1994). These services include help with activities of daily living (ADLs) (e.g., bathing, dressing, eating, and with instrumental activities of daily living (IADLs) (e.g., shopping and preparing meals) and expand an individual’s capacity and control in life to perform daily activities at home or at work (U. S. Department of Health and Human Services, 2002).

With the aging of the U. S. population over the next few decades, there will undoubtedly be a growing demand for PAS. Projections show that the need for such services will increase from 13 million in 2000 to 27 million in 2007 (U. S. Department of Health and Human Services, 2003). Although the current majority of assistance with ADLs and IADLs is being provided by informal caregivers (LaPlante, Harrington, & Kang, 2002), personal assistants (PAs) supplement the efforts of informal caregivers and enable adults with chronic disabilities to sustain some functional level and quality of life in a community setting (Caro, 2001; Eustis & Fischer, 1992; Given et al., 1992; Stone & Weiner, 2001). Those who lack available care and support may experience severe consequences including problems with nutrition and the potential for secondary health problems (LaPlante et al., 2002).

With origins in the United States civil rights and consumer movements of the 1960s, the disability and independent living movements, which began in the 1970s, helped reframe disability more as a social construct than an illness (DeJong, 1979; Shogan, 1998), and gained momentum with passage of the Americans with Disability Act in 1990 (West, 1996). During the past several decades, a growing interest in the consumer direction of PAS and home and community based-services has evolved in both the aging and disability population (Kassner & Williams, 1997; Meiners, Mahoney, Shoop, & Squillace, 2002; Simon-Rusinowitz, Bochniak, Mahoney, & Hecht, 2000; Simon-Rusinowitz & Hofland, 1993). Literature on three themes related to PAS is reviewed below: Autonomy and Choice, Consumer-Directed Services, and Policy and Workforce Issues.

A. Consumer-directed care

Autonomy and choice

An appealing part of the philosophy of consumer-directed services is that the consumer, not the service provider, maintains locus of control thus preserving consumer independence (Cavallo, 2002; Eustis, 2000; Katz, 1998; Kumar, 1998; Theve-Gibbons, 2001). During the 1970s, individuals with disabilities initiated the Independent Living Movement and laid groundwork for the assimilation of people with disabilities into communities through the three part approach of deinstitutionalization, mainstreaming, and normalization (Anderle, 1995; Batavia, 2001; Cohen,

1988). Consequently, advocacy for consumer direction is a vital cornerstone for home and community-based services (HCBS) and for the preservation of individual autonomy (Batavia, DeJong, & McKnew, 1991; Kapp, 1996).

While people in the disability community have been advocating for enhanced choice in being able to select and direct their own long-term care for some time (Batavia, 1998; Kapp, 1996), evidence demonstrates that there have been few improvements over the course of the past several years in quality of life for people needing personal assistance services (Gibson, 2006). A recent AARP report on changes in health and long-term care supports for people with disabilities indicates that in 2005 people were more likely than in 2002 to expect the quality of their lives to worsen over the next four years (70% vs. 55%) (Gibson, 2006). This may be due in part to low staffing levels that lead to poor quality of care and the growing difficulty in recruiting and retaining direct care workers. In addition, peoples' concerns about the inability to pay for long-term care services and supports reportedly doubled between 2002 and 2005 (12% to 24%) (Gibson, 2006). While people with disabilities are most fearful about losing independence and mobility, affordability of long-term care services, which are largely uninsured, is of great concern because it is an important variable in a person's ability to preserve independence (Benjamin, 2001).

Although people with disabilities need services and support to live as independently as possible, paid help is uncommon and most respondents (75%) in a recent survey report receiving assistance from family members, usually spouses or children; only 20 percent reported receiving services and support that were paid for (Gibson, 2006). Unmet need for assistance with daily activities continues to be a significant issue for people who want to live as autonomously as possible and exercise choice and control over decisions that impact their health and basic daily activities (Gibson & Verma, 2006). Recommendations in the literature urge states to act promptly under Medicaid's current flexible guidelines, to implement quality home and community-based long-term systems of care in which people with disabilities can experience a self-empowering model of autonomy and choice and receive primary, preventive, and specialty care that is integrated with HCBS (Eustis, 2000; Kapp, 1996; Stupp, 2000).

Consumer-directed services

In the past, disability was viewed as a medical condition that precluded individuals from participating in the mainstream of life (Dautel & Frieden, 1999; Holzschuh, 1994). It was not uncommon for people with disabilities to experience the impoverishment of isolation and to be segregated from society, and large institutions were frequently domiciles for people coping with severe physical long-term disabilities (Dautel & Frieden, 1999). Subsequent to Medicare legislation in 1965, financial incentives were provided so that people with disabilities could receive care in nursing homes (Dautel & Frieden, 1999; Litvak, 1998). In an effort to shift legislative bias away from the nursing home model of long-term disability care, while Medicare and Medicaid policy were being created, the disability rights movement organized and generated another approach to long-term care (e.g., PAS delivered in non-institutional settings, such as homes) that meets the diverse needs of people with disabilities while allowing them to live independently with support and to actively participate in their communities (Dautel & Frieden, 1999).

The disability community is largely responsible for the vision and promotion of consumer-directed services (DeJong, Batavia, & McKnew, 1992), although shortened hospital stays and medical technology that facilitate home care have also fueled and created the trend toward consumer-directed care (Coleman, 2000). With the intent of yielding to the ethic of

consumerism (Doty, 1998) and allowing Medicaid clients maximum consumer-direction and greater choice capacity, a large-scale public policy experiment called the “Cash and Counseling” Demonstration/Evaluation was designed to test practicability of a consumer-directed approach to financing and delivering personal assistance services (Doty, 1998). Findings from the assessment show that consumer-directed care reduces administrative costs (Doty, 1998). It also allows people to tailor PAS to meet individual needs; money used in this way results in increased personal empowerment and a more ideal consumer-controlled paradigm (Cohen, 2002; Cowan & Watson, 2002; Litvak, 1998; Schnur & Holland, 2002). Similar findings from a Louis Harris and Associates (1993) poll show that consumers have a higher level of satisfaction when they are involved in their own care management. Researchers also suggest that when people with disabilities use PAS, there is more commitment to employment situations and increased community involvement (Richmond, Beatty, Tepper & DeJong, 1997). PAS currently exist in many states and 32 states have made it an entitlement under the Medicaid program (Robison et al., 2007).

Approximately 13.2 million non-institutionalized adults receive about 31.4 hours each of personal assistance per week amounting to 21.5 billion hours of assistance per year (LaPlante et al., 2002). While such services provide necessary help with activities of daily living and instrumental activities of daily living, it is estimated that only 16% of the total number of hours is paid, representing \$32 billion in home health care services paid per year (LaPlante et al., 2002). Under Medicaid’s personal care services, only attendant services are provided; however, when financing PAS under a Home and Community-Based (HCBS) waiver, many more services can be provided. Personal care services are not included in Connecticut’s Medicaid State Plan benefit package; however, the state does provide PAS under Medicaid through some of their HCBS waivers.

Policy and workforce issues

While the disability community has been successful in promoting their vision of long-term care, there remains a strong institutional prejudice in both federal and state legislative policies, which provide financial support for such services (Dautel & Frieden, 1999). Although an association between access to PAS and significant outcomes including functional capacity, maintenance of good health (Prince, Manley, & Whiteneck, 1995), productivity (Richmond et al., 1997), and community integration (Dautel & Frieden, 1999) has been acknowledged in the literature, there is still no expansively implemented system guaranteeing the availability of these services to the people needing them. There are also considerable differences between states in the way in which programs are managed and the extent to which program recipients can select and direct services (Dautel & Frieden, 1999).

In the past, the majority of caregiving was accomplished informally, in private sectors, usually by family members, neighbors and friends and most likely without monetary compensation (Litvak, 1998; Stone, 1999). Over time, care needs and the way care is provided have changed (Schmieding, 2006; Stone, 1999). Currently, care is increasingly being provided by people who do it for payment and by professionals who receive their work identity through caring (Kane, Kane, & Ladd, 1998; Stone, 1999). While a distinct interest in consumer-directed services and cash allowances for these services is growing, implementing appropriate programs continues to be challenging (Dautel & Frieden, 1999; Stone, 1999). The American health care system is often described as nonadaptive, inflexible, and resistant to consumer choice and thus contributes to the long-term care crisis (Dautel & Frieden, 1999; Ondrejka & Mandeville, 2002). In addition, specific components of consumer-directed care, such as hiring, training, managing, and paying personal assistants are problematic (Simon-Rusinowitz et al., 2000). For example,

there is considerable variance in consumers' capacity and willingness to orchestrate their own personal care services including the challenges of finding, hiring and managing PAs for the hours needed (Simon-Rusinowitz et al., 2000). Some consumers want the responsibility of managing their own care, but others may find it burdensome or may be mentally unable to hire and manage their own assistants (Doty et al., 1994). The literature suggests that while PAS requires a shift in thinking from a model of dependence to one that is more autonomous, this may involve competency issues related to employers and their care management including: personal assistant recruitment, training and retention; defining PA duties; carrying out tax and payroll functions, and disciplining and discharging assistants (Flanagan & Green, 1997; Holzschuh, 1994; Kane et al., 1998; Simon-Rusinowitz et al., 2000; Simon-Rusinowitz et al., 1997; Saxton et al., 2001; Smith, 1999; Tilly & Wiener, 2001).

The expansion of Medicaid has been a strong influence in the development of the PAS workforce (Kaye, Chapman, Newcomer, & Harrington, 2006). Between 1989 and 2004, the need for personal assistance grew and the number of individuals requiring help with ADLs increased by more than half during this same time period as well (Kaye et al., 2006). Data from the Current Population Survey (CPS) indicate that between 1989 and 2004, the workforce that provides noninstitutional services has tripled. However, low wages, lack of benefits, and high job turnover rates are problematic. These issues must be addressed in order to ensure a stable and well-trained workforce in the future that will be able to meet the increasing demands of people with long-term care needs (Kaye, et al., 2006). A number of workforce barriers impact the success of the PAS model. These barriers include: an hourly wage below the national minimum wage over the past decade; increasing health insurance premiums that limit agencies from offering benefits; problems with the state-funded systems relying on public policy and economic conditions that are not as responsive as could be to the private sector, and unstable or declining funding levels (American Network of Community Options and Resources, 2002; Center for MassHealth Evaluation and Research, 2002). Paid sick and vacation time, workers' compensation, and a cap on number of working hours are ongoing areas of concern (Kapp, 1996; Marini & Shefcik, 1996; Tilly & Wiener, 2001). If current pressures to limit Medicaid spending result in reducing PAS in the community and the number of PAS work hours are also reduced, the workforce serving people in the community will continue to remain unstable and put the well-being of people needing long-term care at risk. Providing adequate compensation and benefits for direct care workers are important areas in the forefront of PAS policymaking that continue to warrant attention (Dautel & Frieden, 1999; Litvak, 1998; Stone & Wiener, 2001). In addition, a national PAS policy would afford assistants more protection under existing laws, and include benefits such as workers' compensation while reducing mismanagement or mistreatment by employers (Batavia, 1991; Kane, 1995).

Under present Medicaid guidelines, states have the opportunity to oversee quality home and community-based long-term care services that are increasingly being sought by consumers with disabilities (Alliance for Health Reform, 2006). At the state level, the challenge is to develop and effectively administer a long-term health care system for recipients with disabilities that is sound financially and provides consumers with high-quality choices from which to select in the most integrated setting suitable (Dautel & Frieden, 1999). State initiatives for the long-term care workforce have included the following as options: wage pass-throughs to increase wages and benefits; increasing health insurance and mileage reimbursement; implementing required training; creating job levels and career ladders in public programs; instituting new workforce groups and including previous welfare recipients; providing opportunities for workers to discuss concerns related to long-term care employment such as wages, benefits, job quality and security quality issues (Ebenstein, 1998; Litvak, 1998; Stone & Wiener, 2001; Turner & Street, 1999).

Little quantitative research has examined workplace interventions or workforce barriers affecting the quality of care and quality of life of those requiring assistance services. Several surveys have explored related policies and organizational aspects of PAS emphasizing: eligibility, cost-effective care coverage, payment, and consumer satisfaction (Aronson & Neysmith, 1996; DeJong et al., 1992; Gruman, Kellett, & Porter, 2003; Simon-Rusinowitz et al., 1997; Smith, Fernengel, Werkowitch, & Holcroft, 1992). Nationwide, two-thirds of Medicaid's Personal Care Services, the largest source of financing for Home and Community-Based Services (HCBS), covered services for individuals with developmental disabilities and mental retardation, while the remaining one-third supported individuals with disabilities living in their homes in the community (Doty, Kasper, & Litvak, 1996; Kassner & Shirey, 2000). In an effort to better understand the extent of the long-term care problem, many states are updating their profile of the workforce by gaining important survey information including: demographic features; levels of education; wages and benefits; distribution, and worker motivation (Center for MassHealth Evaluation and Research, 2002; Mahoney, et al., 1998; Simon-Rusinowitz, et al., 1997). People with disabilities strongly prefer to live in their own homes and overall want more direct control over what long-term care services they receive and when they receive them (Gibson, 2003). It is important to continue supporting publicly funded, consumer-directed care services in order to enhance the quality of life for people by promoting independence, self-esteem and sense of purpose (Disch, 2003).

III. Methodology and Analysis

A. Introduction

The data for this report come from the broader Medicaid Infrastructure Grant study. The 2006 report comprehensively examined issues regarding employment and people with disabilities. As part of this larger study, mail surveys, interviews, and/or focus groups were used to reach people with disabilities, providers, and employers.¹ Questions in the instruments were related to employment and people with disabilities, and covered topics such as employment challenges, job supports, accommodations, and assistive technology. Additional questions addressed topics pertinent to each specific respondent group.

While not the focus of the larger study, detailed questions regarding PAS and employment were included in all consumer forms and in the employer mail survey.² People with disabilities were asked for the most comprehensive information about their experiences with PAS in all mail surveys, interviews, and focus groups. A separate, detailed set of questions regarding PAS was included in the consumer surveys and interviews, and the focus groups and key informant interviews with people with disabilities contained open-ended and probing questions regarding PAS, designed to elicit people's views and discussion regarding these services. Although no question in the provider focus groups or key informant interviews specifically asked about PAS, discussions about personal assistance as a needed employment support were initiated by provider respondents in one-quarter of the provider interviews and focus groups. There were no specific questions or discussion about PAS in either the employer interviews or focus groups.

¹ Mail surveys were not used with providers; interviews were not used with employers.

² Employers were only asked one PAS question, inquiring how easy or difficult it would be to "provide someone to assist the person with job related duties, such as a personal assistant, reader, etc." The great majority of responding employers (85%) indicated it would be difficult or very difficult to do so.

This report describes a subset of these findings and focuses solely on results pertaining to PAS. These services can include help with activities of daily living (e.g., bathing or dressing), health-related functions (e.g., medication administration), behavioral intervention (e.g., monitoring or redirection), and instrumental activities of daily living (e.g., cooking, shopping, or transportation). Having PAS, either at home or work, is an essential support for some people with physical or other disabilities. As an employment support, personal assistance services play an important role for many people with disabilities. Inadequate or lack of PAS services can limit the employment experiences or opportunities of people with disabilities. The purpose of this report is to describe the PAS experiences and views of respondents who participated in the larger MIG study. It also explores the reasons why an unexpectedly low number of people reportedly use these services.

B. Focus group and key informant interviews

Focus groups are in-person group discussions with a small number of respondents. Typically, focus group and key informant participants are relatively similar individuals who are chosen based on their ability to provide specialized knowledge or insight into an issue being studied. Unlike individual interviews, focus groups generate ideas and information through group discussion. Focus groups provide a rich and diverse body of data which is especially important in exploratory studies or in the preliminary stage of a research study (Stewart & Shamdasani, 1990). The focus groups were moderated by a facilitator, with an assistant taking notes and running the tape recorder. The facilitator was given the latitude to further explore issues or comments that arose from the discussion in each group, in addition to the questions from the focus group guide.

The key informant interviews were qualitative, in-depth telephone interviews of people with extensive knowledge of disabilities, employment, and services and supports beneficial for people with disabilities. Only results of the focus groups and key informant interviews with people with disabilities and service providers are included in this report, as the employer groups did not include questions related to PAS.

Instrument development

The focus group and key informant interview guides for the MIG study were developed from issues discussed in the literature with input from the MIG Steering Committee members. The guides included a set of mostly open-ended questions followed by probes. The focus group questions discussed many of the same issues covered by the key informant questions, but contained more probes in order to generate discussion. Separate instruments were designed for people with disabilities and service providers, with some overlap of questions. Approximately 15 grand tour questions covered topics related to employment, including job supports, employment challenges, accommodations, and assistive technology (see Appendices A, B, C, and D).

PCA Measures

As with the mail survey, the focus group and key informant interview guide for people with disabilities included additional questions about PAS experience and the use of personal assistance services at work. Questions used in the consumer focus groups relating to PAs included a question asking the participant to describe any experiences they have had with

personal assistants or home health aides at a job. Consumer key informant interviews asked a series of short questions related to personal assistant and included the following:

- 1) Do you require personal support, i.e., home health aides, personal assistants, etc.?
- 1a) Approximately how many hours per week do they work with you, altogether? [if they cannot answer, ask in a typical day]
- 1b) Would you need personal assistants or aides help you to get ready for work?
- 1c) Would you need them to transport you to and from work?
- 1d) Would they need to stay with you for part or all of your work day?
- 1e) Do you have a backup plan if a personal assistant is very late or absent?
- 1f) If you hire your own personal assistants, please describe the hiring process that has been most effective for you.

Recruitment and response

As part of the larger study, key informant interviews and focus groups were completed with respondents from all three groups: people with disabilities, service providers, or employers. However, as this report focuses on PAS, the recruitment methods and results for the employer focus groups and interviews will not be included, as they did not address PAS. Although the guides for providers did not include specific questions regarding PAS, respondents in two out of eight provider focus groups and five of nineteen provider interviews did discuss PAS, and those results are included in this report (see Medicaid Infrastructure Grant Needs Assessment: Final Report for a complete description of all the focus group and interview results, which is accessible at: <http://www.brs.state.ct.us/StrategicEmployment.htm>).

Focus group participants were recruited using a variety of methods. Using suggestions from the research team and Steering Committee members, various organizations and agencies from across the state were contacted. Purposeful sampling was used to reach various types of providers and people with all different types of disabilities (physical, mental illness, intellectual, vision, or hearing disabilities). Each provider or disability focused group or organization was invited to participate in the project, and offered a one time payment in exchange for them to invite participants and host the focus group. A total of 27 focus groups were conducted with people with disabilities and providers across the state: 18 with people with disabilities or their family members, 8 with service providers, and 1 mixed group, for an overall total of 234 focus group participants (see Table 1).

Table 1. Focus Groups

Category	Total focus groups	Total of participants
People with disabilities or their family members	18	147
Service providers	8	81
Mixed person with disabilities and providers	1	6
Totals	27	234

Steering Committee members also provided the names of people in Connecticut and in other states to contact for the key informant interviews. The respondents were chosen for their first-hand knowledge of or experience with disabilities, and employment services for people with disabilities. Letters were sent out by mail or email inviting each key informant to be interviewed over the telephone. A follow-up call was placed by a member of the research team to determine if they were willing to participate and to set up the interview date and time. Interviews varied in length, from 20 to 45 minutes, with most taking approximately 25 minutes to complete. Twenty-nine key informant interviews were conducted with people with disabilities (n=10), or providers or policymakers (n=19). See Table 2 below.

Table 2. Key Informant Interviews

Category	Total participants
People with disabilities	10
Providers/policymakers	19
Total key informant interviews	29

Analysis

With consent of participants, the focus groups were audio taped to allow for an accurate transcription and identification of supportive quotations as appropriate. Detailed notes were taken at each focus group by an assistant assigned only to that task. These notes were transcribed using the audiotapes for further clarification. For the key informant interviews, the interviewer took detailed notes, reading them back to the respondent for further clarification if necessary. These notes were then transcribed in full immediately after the conclusion of the interview.

For both the focus group and key informant interviews, content analysis was performed in accordance with standard qualitative techniques (McCracken, 1988). Transcripts were analyzed line by line in order to identify and interpret discussion content. Two researchers independently analyzed each transcript, reaching a consensus if interpretations were different. Major concepts supported by direct quotations were organized into common themes using the constant comparative technique (Glaser & Strauss, 1967). Additional themes were included until no new topics were identified. Like statements were then explored and compared to refine each theme and ensure a fuller understanding of each. Supportive quotes were included throughout the analysis. Using this technique, multiple distinct themes were identified for each key informant interview and focus group. The data from each group of respondents (people with disabilities, providers, and employers) was then analyzed in a similar fashion in order to identify salient topics or areas of interest for each group. For this report, themes related to personal assistance services are described in the results section below.

C. People with disabilities in Connecticut: Mail survey and interviews

Unless otherwise noted, the following describes the research methodology and analysis for the overall MIG study, as this report examines a subset of results from that study. Three different methods were used for the mail survey and interviews with people with disabilities: mail surveys, telephone interviews, and in-person interviews. The goal was to use all three methods with each waiver or program population in an effort to obtain a substantial amount of diverse and in-depth information while minimizing respondent burden.

Instrument development

The mail, telephone, and in-person instruments were developed by the research team, incorporating important issues raised in the literature along with content areas the Steering Committee or research team felt were important to investigate. The mail survey and interview instruments were to address topics which could influence the successful employment of people with disabilities, including personal assistance services. Although the literature showed that some issues may have a greater effect on certain disabilities than others, effort was made to include as many concerns as possible, providing a comprehensive look at people with disabilities in Connecticut.

The instruments comprised both quantitative and qualitative questions. The open-ended format of the qualitative questions gave the interviewees the freedom to fully describe their experience or views. Using standardized probes, telephone and in-person respondents were encouraged to provide insights and views on a range of issues. The mail survey was developed from the telephone interview instrument. Consistent with standard mail survey practices to reduce respondent burden, fewer qualitative questions were included in the mail survey. The final survey instrument comprised one form containing the employment questions, while a separate booklet addressed PAS, demographics and other concerns.

The personal assistance services (PAS) section began with preferences regarding self-directed care and management of personal assistants. Further questions addressed experiences using PAS at home and at work, satisfaction, problems encountered using PAS, and self-efficacy regarding PAS. Additional questions covered demographics, disability status, health, transportation and other questions (see Appendix E for the full mail survey and telephone instruments).

A corresponding telephone and in-person PAS/demographic interview form was developed. It comprised the mail survey questions plus additional open-ended questions and probes. For the in-person interviews only, a qualitative question using vignettes was included to further explore respondents' wants and opinions on self-directed care and personal assistance services (Appendix F). The vignettes described three different approaches concerning hiring, managing, and paying personal assistants. The interviewer read each approach out loud, giving the respondent a sheet to read along with. After all the approaches were read, the respondent was asked, "Which approach do you like the best?" Standardized probes were also included to further explore the respondents' views.

This report includes information on all PAS related variables, as well as questions related to demographics, disability, and health.

Research sample

In an effort to reach residents of Connecticut who have any type of disability, residents who participate in any of Connecticut's Home and Community Based Waiver Programs or other service programs were recruited for the overall MIG study. This included participants from the Medicaid Personal Care Assistance, Acquired Brain Injury, and Department of Developmental services (DDS) waivers, as well as participants in the Medicaid for the Employed Disabled program (Connecticut's Medicaid Buy-In program) and participants from several aging services programs including the Self-Directed Care program and the Connecticut Home Care Program for Elders (both Medicaid waiver and state funded). Although separately defined on paper, each waiver or program may serve people with varying disabilities, who may use paid personal care services. As no waiver program is currently available for people with mental illness disabilities, participants in this population were reached by other means, primarily through mental health authorities across the state.

To include people with all different types of disabilities living in Connecticut, databases from six different waivers or programs were used:

PCA Waiver

The Personal Care Assistance (PCA) waiver provides funding for personal care assistance services for adults age 18 to 64 who have chronic, severe and permanent physical disabilities and who wish to reside in the community (as of 2006 there is no longer an upper age limit). Eligible candidates for this waiver seek to remain in the community and would otherwise require nursing facility care. Participants must also be capable of self-direction, that is, able to hire, fire, manage, train and supervise their own personal assistants.

ABI Waiver

The Acquired Brain Injury (ABI) waiver was implemented effective in January, 1999, to address the needs of persons with acquired brain injuries who would otherwise require services in an institutional setting. The waiver serves people between the ages of 18 and 64 and who meet all other HCBS Medicaid eligibility requirements. The waiver employs the principles of person-centered planning to develop an adequate, appropriate and cost-effective plan of care from a menu of twenty-one home and community-based services to meet the person's needs in the community.

DDS Waivers

The Individual and Family Support (IFS) waiver provides in-home, day, vocational, and family supports services for people who live in their own or family home. The Comprehensive Supports waiver is for services delivered in licensed settings, and provides for the vocational and in-home services needed for people who require a more intensive level of support to remain in their own or family home.

MED Program

The Medicaid for the Employed Disabled program allows persons with a disability to engage in employment without risking eligibility for needed medical services through the Medicaid program. In general, an eligible person with a disabling condition who is employed can qualify for Medicaid without the use of spend-down while earning income in excess of traditional income limits.

Connecticut Home Care Program (Waiver, State Funded Program, Personal Care Assistance Pilot Program)

The Connecticut Home Care Program for Elders (CHCPE) is a state and federally funded program that provides an array of home care services for people age 65 and older. The program helps eligible Connecticut residents remain at home instead of prematurely going to a nursing facility. Depending on the eligible person's health and living circumstances, the services offered may include home health services, homemaker services, visiting nurse services, adult day center services, adult foster care services, chore services, care management, home delivered meals, companion services, emergency response system, minor home modification depending upon availability of funds and assisted living services in approved managed residential communities. A subset of these participants self-direct their own care (referred to as the SDC group).

Benefit Offset Demonstration Project

The Benefit Offset Demonstration Project (BODP) is a Social Security Administration funded demonstration program which encourages those who receive an SSDI cash benefit to increase the amount they are earning through employment. Those randomly assigned to take part in the BODP can earn more than the Substantial Gainful Activity (SGA) monthly limit and not lose all their Social Security Disability Insurance cash benefit.³ This database consists of a representative disability group with substantial work experience, most of who were working either currently or in the recent past. All were identified as having a disability and receiving SSDI. Any of the first 300 names from the BODP database who had not responded to the BODP letter of invitation made up the pool of potential BODP participants for the MIG survey.

For the overall MIG study, contact information for 1,962 participants was combined from these waivers or programs for the mail surveys, telephone interviews, and in-person interviews. The aim was to complete mail surveys, telephone interviews, or in-person interviews with individuals from each waiver or program, with a target goal of 600 total completed surveys or interviews. To reach this goal, approximately 250 names were randomly chosen as potential participants from each program. All participants in the PCA waiver program were chosen as these

³ To be eligible for disability benefits, a person must be unable to engage in substantial gainful activity (SGA). A person who is earning more than a certain monthly amount (net of impairment-related work expenses) is ordinarily considered to be engaging in SGA (Social Security Administration, October, 2006). In 2005, the SGA limit for most people with disabilities was \$830 a month; this increased to \$860 in 2006, and \$900 in 2007. Ordinarily if a person with disabilities earns more than the SGA in one month, the person is not eligible for any of their SSDI cash benefit for that month. This applies whether a person earns \$1.00 or \$1000.00 over the SGA in that month. In contrast, BODP participants lose only \$1.00 of their SSDI cash benefit for every \$2.00 they earn over the SGA.

participants were considered a target group for the national Medicaid Infrastructure Grant project as well. Only mail surveys could be completed with the PCA and ABI waiver recipients, as no telephone numbers were provided for these two waiver programs. This precluded the opportunity to conduct any qualitative interviews with respondents known to be on either of these waivers. Due to a lack of program or waiver database, no mail surveys were sent to people with mental illness disabilities. Instead, interviews were conducted with Department of Mental Health and Addiction Services (DMHAS) clients at two Local Mental Health Agencies.

Recruitment

Pre-notification

To protect each participant's confidentiality, the Bureau of Rehabilitation Services (BRS), part of the state Department of Social Services, first sent each person a letter explaining the research project and including a toll free number to call if they did not want to participate. The letter gave the recipients a two week window to call BRS and decline participation. Use of a pre-notification letter protected the confidentiality of those recipients who did not want to be contacted, and gave them a chance to decline participation before any surveys were sent or any calls made. After the two week window was passed, the contact information for the remaining clients was given to the researchers.

The remaining potential participants from the CHCP, SDC, MED, BODP, and DDS waiver or program were then randomly assigned to one of four groups (mail survey, telephone interview, or in-person interview).

Methods

Mail surveys were sent to randomly selected names from the SDC, MED, DRS, DDS, and BODP databases who did not respond to the initial pre-notification letter. In an effort to reach a greater number of ABI and PCA waiver participants, all of those on these two waivers who did not decline participation received mail surveys. Each person in the mail survey group received a personalized introductory letter, the three colored employment surveys (corresponding to currently working, worked in past, or never worked), one white PCA/demographics booklet, and a self-addressed, postage-paid return envelope. If there were no response after approximately three weeks, a second packet was sent.

The personalized letter outlined an incentive for the survey: all participants who sent in a completed survey were eligible to win one of ten \$50.00 gift certificates. The letter also detailed which employment survey to fill out, depending on one's job status. This explanation was also included at the top of each employment form. The PCA form for the mailed survey group included a question regarding current PCA status (currently use, used in past, or never used PCA). Written skip instructions directed the participant to go to the next appropriate question. For example, respondents who indicated they had never used these services were instructed to skip the section regarding experiences using PCA. A description of personal assistance services was provided at the top of each PCA booklet to help respondents determine their PCA status: "People sometimes employ someone to help them with tasks like personal care, mobility, or communication. This person could be a personal assistant, helper, or anyone else who is paid to help them at home or at work." The definition was deliberately broad in order to encompass the different descriptions of personal assistants used by people on different waivers (for example, personal assistants, independent living skills trainers, or support staff).

Those assigned to the telephone or in-person interview group received a minimum of four telephone calls. Those reached by telephone were given a description of the research project and an invitation to participate. The incentive to receive one of ten \$50.00 gift certificates for completing a survey was also explained. The flexibility to complete the interview at a time and/or place convenient to the respondent was stressed, and interviewers made themselves available for early morning to late evening appointments or calls. To include those potential telephone and in-person respondents who could not be reached by telephone, a mail survey was sent to those with no telephone contact after four attempts. This included those respondents with a not-in-service or wrong number, or those who never answered the phone. To reduce respondent burden and increase response rate, the researchers retained flexibility regarding the person's assigned group and respected the respondent's choice. For example, a mail version of the survey was sent to any respondent contacted to do a telephone interview who instead wanted to complete the interview by mail.

Without a specific waiver program or access to any central database, additional effort was made to reach those with a mental illness disability. These individuals were reached in two ways: recruitment by counselors at two mental health regional centers, and the snowball technique.⁴ DMHAS vocational counselors and case managers at two regional mental health centers, one in central Connecticut and one in the southeastern part of Connecticut, recruited clients for in-person interviews. The DMHAS clients were personally identified and invited by the DMHAS employees. Only the first names of those DMHAS clients who chose to participate were given to researchers. In-person interviews were then set up through the DMHAS employees at the regional centers. The snowball technique was used to reach other interested participants, using contacts in the community and at a mental health advocacy organization. This resulted in both mail surveys and in-person interviews being completed with those with primarily mental illness disabilities.

24 hour telephone access and suicide protocol

A 24-hour toll free telephone number was established to allow survey respondents to call in if they felt upset by one or more of the mail survey questions. This number was published in the introductory letters. No calls were received during the course of the study. In addition, program managers requested that we develop a full suicidal protocol in the event that an individual contacted us. However, the protocol was never needed.

Response rates

A total of 642 interviews or mail surveys with people with disabilities were completed for the MIG study. Surveys were completed by people with physical, intellectual, and mental illness disabilities. Adjusting for incorrect contact information (both telephone and mailing address), deceased, non-English speaking, or otherwise ineligible participants, this resulted in an overall response rate of 40% for all interviews and surveys combined. When examined by individual survey method, the response rates by method for the MIG study were: 36% mail, 86% telephone, and 38% in-person interviews. There were a total of 131 potential respondents with incorrect addresses and telephones, 29 ineligibles, 8 deceased, and 39 refusals (the last when contacted by telephone). Telephone interviews took an average of 28 minutes (range 12 – 48 minutes), and in-person interviews an average of 41 minutes (range 25 – 58 minutes). A total of 597 respondents completed at least part of the PAS section (491 mail surveys, 87 telephone interviews, and 19 in-person interviews).

⁴ Current participants or contacts refer other potential participants to the study, who then refer people they know, etc., creating a snowball effect.

Analysis

All data were entered into Microsoft Access 2003 tables. This program is suitable to enter both quantitative and qualitative (open-ended responses) information. After data collection was complete, the data were converted to SPSS version 13.0, a statistical software package designed for both simple and complex analysis.

Several types of data response errors occurred that required transformations prior to analysis. One of the most common errors was encountered in the analysis of skip questions. Individuals who answered “no” to a skip question were theoretically expected to skip to the next designated section. However, several respondents to the mail survey provided quantitative data for questions that should have been skipped. Mirroring analysis conducted in other studies, items embedded within skip questions that were inappropriately answered were re-coded to missing values. This recoding scheme enabled comparability between the results of each of the survey techniques (e.g., telephone interviewers skip the appropriate skip questions). As is typical with survey data, data entry errors occurred, many requiring some type of data transformation. Most were straightforward and easy to correct (i.e., an individual’s date of birth that appeared as 1466 would be rechecked against the original survey and corrected as appropriate).

A three-step statistical strategy was employed in this study. First, a preliminary analysis determined the distribution of the sample across the independent variables (survey items) in the study. The study sample was first categorized into two groups: those who reported having either no PCA experience versus those who had PCA experience. Next, data were analyzed question by question, with a series of basic tests computed: frequency, average, and percentage. All variables of interest or related to personal assistance services were examined. The variables were then simplified by eliminating extraneous variables and by reducing the number of divisions of multi-categorical variables. A comparison of the response distribution both within and between groups was performed. Differences between groups were analyzed using Chi-Square, Fisher’s Exact Test, and T-Tests for categorical and continuous data, respectively. Actual significance levels (p values) are documented in the report.

Some respondents to the mail survey appeared to misunderstand the definition of PCA and indicated they had experience with a PCA when in fact they had agency-supplied home health aides. This confusion was evident from responses to open-ended questions, particularly in the CHCPE group. Thus, analyses for the survey responses are limited to people under age 70 in this report.

Analysis for open-ended, qualitative responses was conducted in the same way as for the focus groups and key informant interview open-ended responses. Any themes identified pertaining to personal assistance services are reported in the results section below.

IV. Focus Groups and Key Informant Interviews Results

Analysis of the focus group and key informant interviews was done separately for people with disabilities and service providers. The following results express the multiple views and experiences of people with disabilities and service provider participants.

A. People with disabilities focus group and key informant themes

Respondents in four out of the eighteen focus groups of people with disabilities and four of ten key informants with disabilities provided information about personal care assistance. There were no comments made about personal care services in the one mixed focus group of people with disabilities and providers. A number of themes emerged from the focus groups and key informant interviews with people with disabilities. These are arranged in the following order:

- PCA services at home
- PCA services in the workplace
- Anticipated need for PCA services
- Recruitment challenges
- Management issues
- Retention barriers
- Family caregiving burden

PCA services at home

Respondents report that they use between 5-42 hours of personal care services monthly and that they use these services mostly at home to assist with getting ready for work or school. In addition, most people with disabilities who were interviewed report that they have a back up plan if a personal assistant is very late or absent that includes using people others have used or hiring friends and family to help.

I have a PCA that helps me get up in the morning, get me dressed, get me my breakfast, and get me off to school.

I have three brothers as temporary PCAs. They help me with dressing, bathing, and feeding, and then I'm off to school.

PCA services in the workplace

Respondents who have help from personal care assistants at work indicate that PCAs typically assist them during work breaks or help them with aspects of work that are difficult to complete because of physical limitations. Several people with disabilities mentioned that they would like flex hours or a flexible schedule of assistance for PCAs so they can choose the hours their PCA helps them. Others report that while they do not need help getting ready for work, they need a PCA to transport them to and from work.

My PCA comes in to help me on my break (15 minutes is not enough) and stays for one hour. Need FLEX HOURS.

For me, flex time is important – levels of desks have to be a certain height, I need some personal care assistance – sometimes needing help putting files away or helping me reach things.

Some people who do not have PCAs at work report that they would like to have personal assistance services made available to them so they can participate in work related activities.

I need a PCA for conferences so I can attend them.

Anticipated need for PCA services

Respondents who are not currently using PCA services foresee a time when they will need assistance with the activities of daily living and/or instrumental activities of daily living.

Eventually I'll need getting a lift and a PCA to help me, this would help me at home to get ready for work.

Recruitment challenges

Some people with disabilities report that they typically find PCAs through the newspaper, hospital, a friend, or an agency. Some report that people hired from agencies are unreliable and that communication problems with them are often disruptive to the services they receive.

For years I worked with agencies and the agencies are not reliable. I had so many cases of horror – left alone, verbally abused, people stealing from my home...one of the aides told me I was too fat and she couldn't lift me.

I get my PCAs through an agency. They don't call me when there is a change in someone's schedule, they'll call me halfway through the night.

Management issues

Respondents indicate that it's difficult to find PCAs who are cooperative and willing to do what they're asked to do. Relational difficulties sometimes arise in trying to resolve conflicts or when PCAs are over-demanding or disrespectful to employers. In some cases, they report feeling unsafe when their assistant is around.

I have PCAs at home, but it is very hard to find people that are accommodating, are reliable, and I mean whatever you do don't hire a friend because I hired a friend and now she is my employee, but we are still best friends. I have a hard time confronting her when she does something wrong.

We've had different assistants living with us. The woman there now is great, but we've had to move out several in the past because they weren't living up to their responsibilities. It was for help with cleaning and cooking. We had to call the police once last year to help one move out.

Like I find sometimes I have to loan them \$5 – \$10 for gas, so that they can come back to help you. Or if they say I'm hungry, you give them a bowl of cereal so that they can better help you out.

I had one that came to help with the laundry. She said she couldn't go down the cellar to do the laundry because she was afraid of spiders.

In addition to navigating difficult relational issues, some people with disabilities also find they need to provide encouragement to PCAs who bring personal issues and problems to work and that this often presents a challenge in managing them.

The amount of money being paid for personal care work is not great. It is so difficult, such a high burnout rate. They sometimes have their own problems. You have to help them along.

It's like counseling your help.

Retention barriers

Some people with disabilities report that they often feel anxious about their ability to retain PCAs and the possibility that if they lose their assistant they will have to ask for help from their family member.

You have to be a really decent person otherwise they won't come back.

My biggest fear is that I don't want anyone leaving me because that will upset my mother because she will have to take care of me.

Family caregiving burden

While family caregiving is appreciated, respondents report that these informal caregivers often experience undue stress and they need someone other than family to provide personal assistance services for them.

I've struggled with the issue of PCA. People think that just because we are disabled and we have parents that don't work that my parents can take care of me 24/7. It's wearing on my mother taking care of me. We need someone who can help me at home to get ready for work. I have a sister also who my mom takes to activities, and my father works late too.

B. Provider focus group and key informant themes

Respondents in two out of eight provider focus groups and five of nineteen key informant interviews provided information related to PCA services. The following themes emerged from these focus groups and key informant interviews.

- Better transitional services
- More accommodations
- Increase disability education for employers
- Improve availability of supports to employers
- Provide more information to people with disabilities

Better transitional services

Providers suggest that better transitional services early on, including the use of PCAs, are needed to prepare young people with disabilities for employment.

The 504 kids [who have a physical disability but don't need Special Ed] – we don't even see those kids until they exit the school system and by then it's too late for a smooth transition to employment. We need to look at home modifications when they are 16 and their parents can't carry them up the stairs, or dealing with personal care attendants. Many school systems don't even refer them to us, but we need to see them early on to prepare.

More accommodations

Providers indicate that human service programs and state organizations tend to be more responsive and more accommodating to people with disabilities because they have a greater awareness of those in the disability population. It was suggested that it may be more difficult for smaller companies to be more inclusive because of the costs involved, but that there may be benefits in doing so.

Many smaller companies can't afford to have someone doing part clerical work and part PA work. Employers who can look beyond and add that to part of the function may benefit.

Increase disability education for employers

Providers report that the existing service system should make it easier to get PCA assistance for employment, and that employers are more receptive to hiring people with disabilities when they understand the need for support in the workplace and know support and help are available.

Most [employers] have needed a great deal of education regarding facts versus myths. They are more receptive to hire when they know support and help are available.

Lack of knowledge about the support networks out there for employers. There are many organizations across CT that will assist employers in their process of hiring and supporting someone with a disability.

Improve availability of supports to employers

Some providers indicate that employers are more willing to hire a person with disabilities when providers make supports available.

That's the bread and butter of my job. If the employer is willing to take the time to hear what I have to say, they are open as long as you are telling them: I have someone who can do the job and I can offer supports to make this happen in the best way possible. I find that employers do not have a problem with that.

Provide more information to people with disabilities

Providers suggest that greater efforts should be made to help people with disabilities learn more about the self-determination model of hiring their own supports because many cannot work or advance at work without the support of personal assistance services. It was also suggested that people with disabilities need to know where to call and ask about obtaining PCA services.

Need personal assistance to encourage [people with disabilities] to go forward.

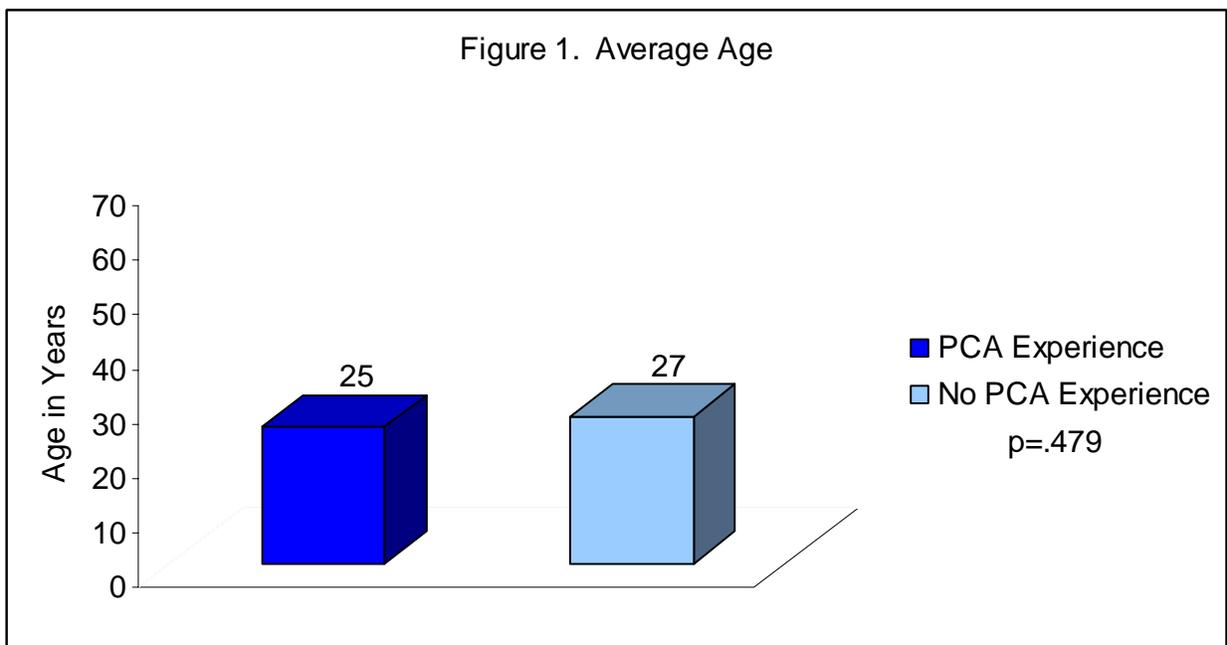
V. Survey Results

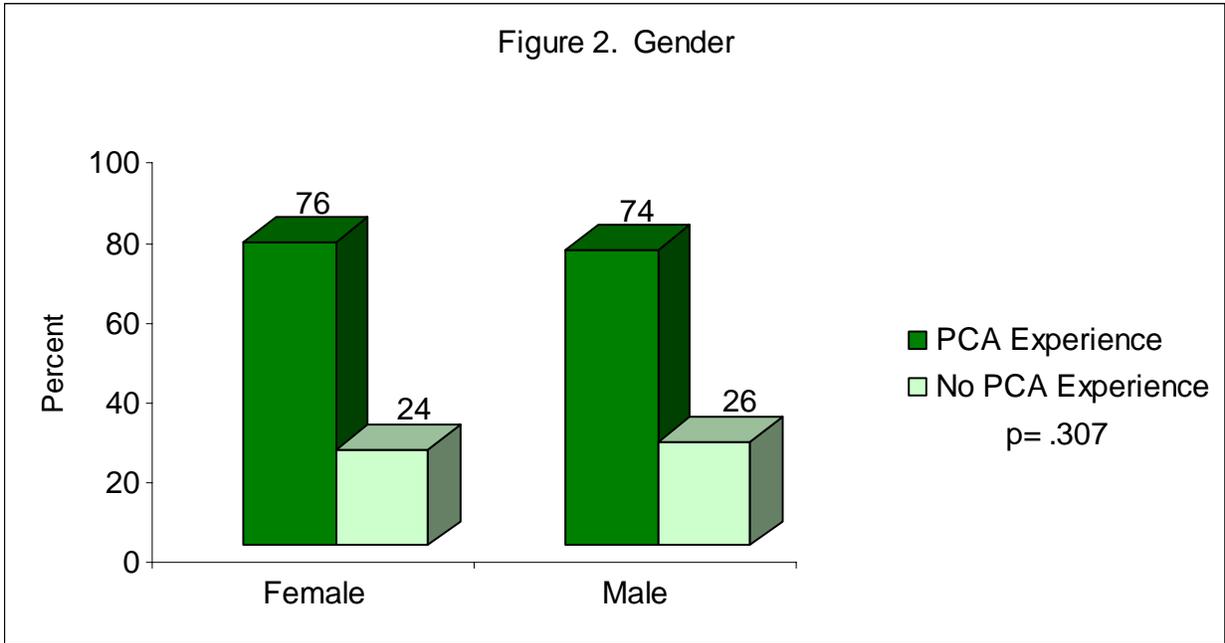
To gain a general overview of people with disabilities, PCA service use, and reasons why many people with disabilities aren't making use of the available PCA waiver services and supports, data for this report were analyzed by looking at variables of interest for those who reported having either no PCA experience (n=131) or those who had PA experience (n=388). Statistical analyses were restricted to those under age 70 and included: Independent Samples T-Test, Chi-Square, and Fisher's Exact Test. Findings are arranged in the following topical areas:

- Demographics
- Education/income
- Self-rated health
- Disability type
- Work experience

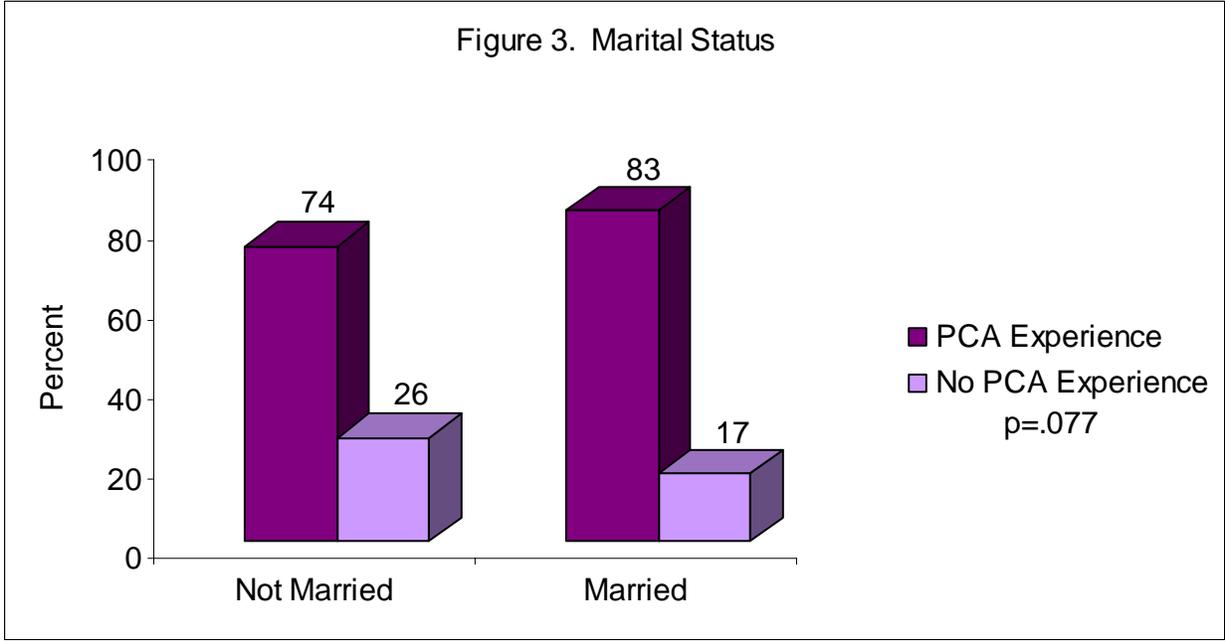
A. Demographics

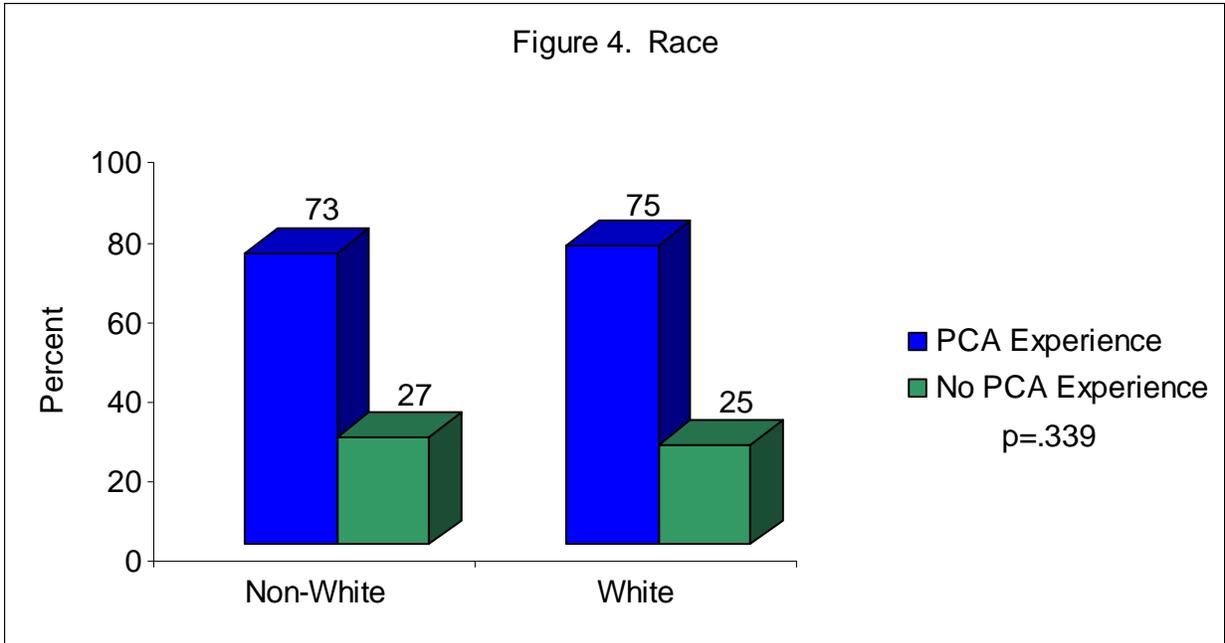
The average age of individuals in this sample with PCA experience and those without PCA experience did not differ significantly (Figure 1). There is also no significant difference by gender (Figure 2).





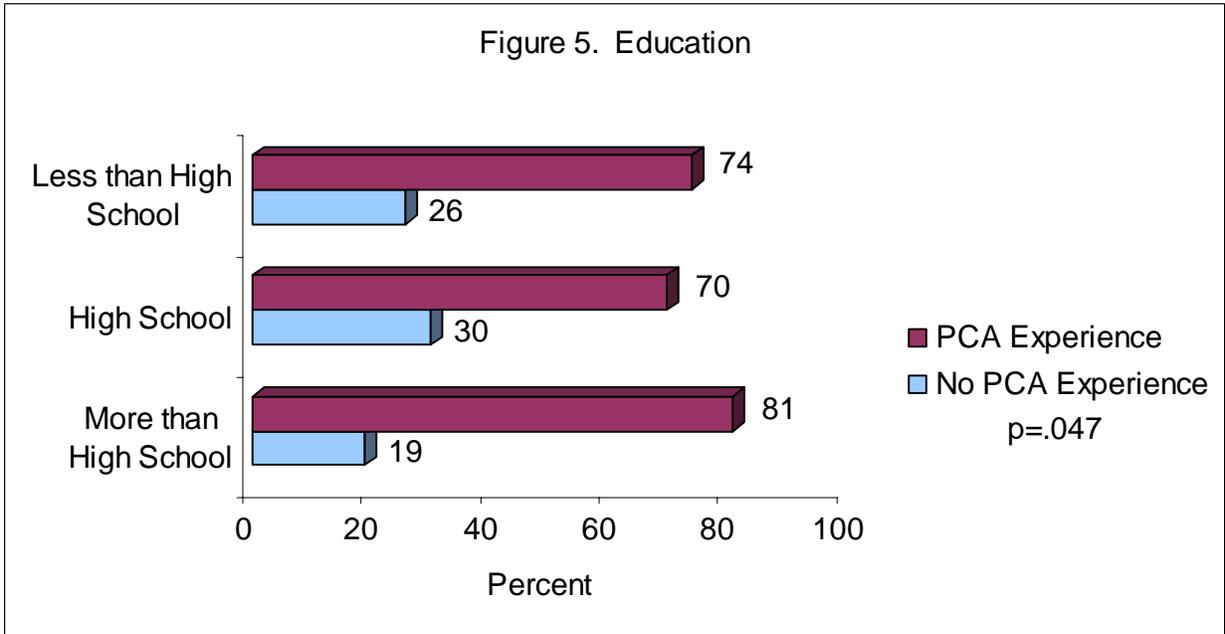
In this sample, married respondents show a trend toward more PCA use ($p < .10$). Of the slightly more than 10 percent of respondents ($n=59$) who report being married, 83 percent have a PCA. This compares to 74 percent of respondents ($n=339$) who report being unmarried and have a PCA (Figure 3). PCA experience does not differ by race (Figure 4).



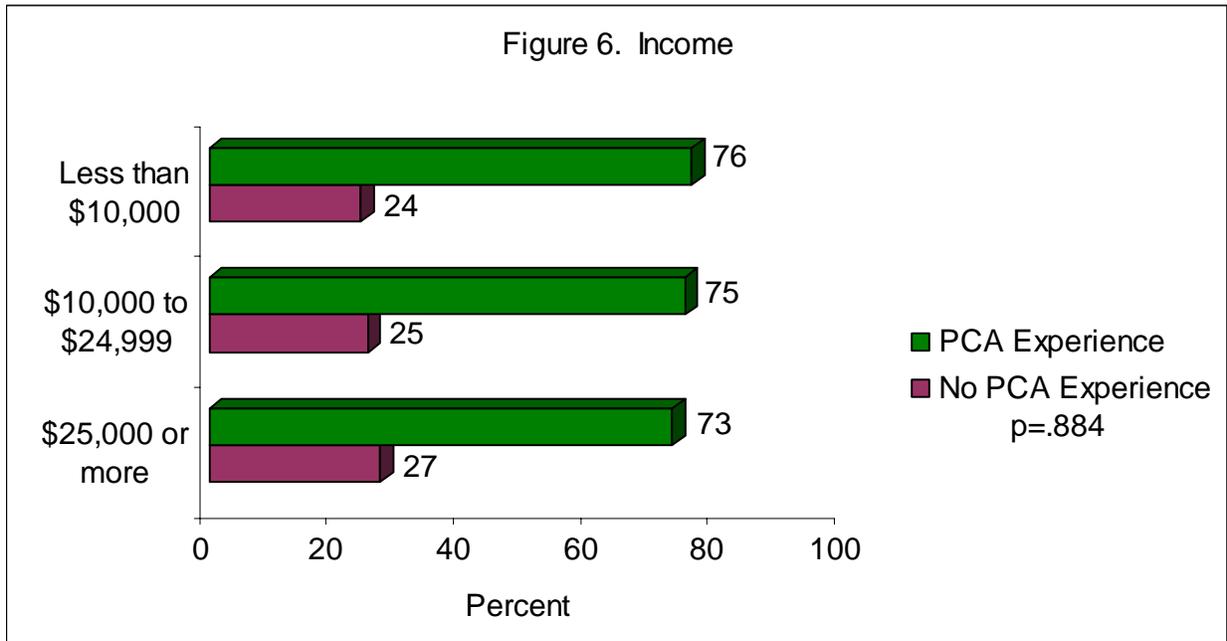


B. Education/Income

A significant relationship was found between the use of personal assistants and educational status ($p < .05$). While 81 percent of those who continued their education after high school have had a PCA, only 70 percent of high school graduates and 74 percent of those who did not finish high school have PCA experience (Figure 5).

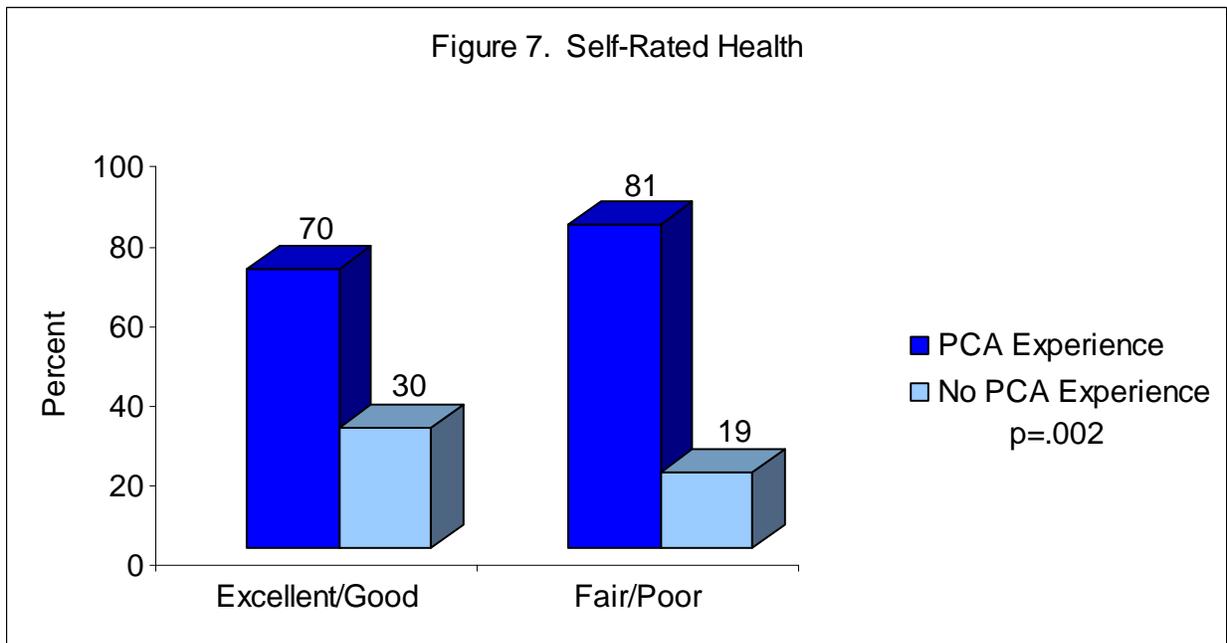


The amount of annual income does not have an impact on PCA experience (Figure 6).



C. Self-rated health

Those who describe their health to be only fair or poor are more likely to have had PA experience (81%) compared to those who consider their health to be good or excellent (70%) (Figure 7).



D. Disability type

The disability type categories are not mutually exclusive. Some people indicated that they had disabilities in more than one category. Therefore, the significance tests indicate whether people who have a particular type of disability (e.g., physical) are more likely than those who do not have that disability to have had a PCA. Data show that two disability types use personal care assistants: physical disabilities ($p=.017$) and intellectual disabilities ($p=.001$). In this sample, 78 percent of people with physical disabilities have PCA experience ($n=250$) compared to 69 percent of people with no physical disabilities (Figure 8). Conversely, only 65 percent of people with intellectual disabilities have had a PCA ($n=104$), compared to 79 percent of people with no intellectual disabilities (Figure 9). Seventy-nine percent of people who report having a mental illness have had PCA experience ($n=70$), compared to 74 percent of people with no mental illness disability, a non-significant difference (Figure 10).

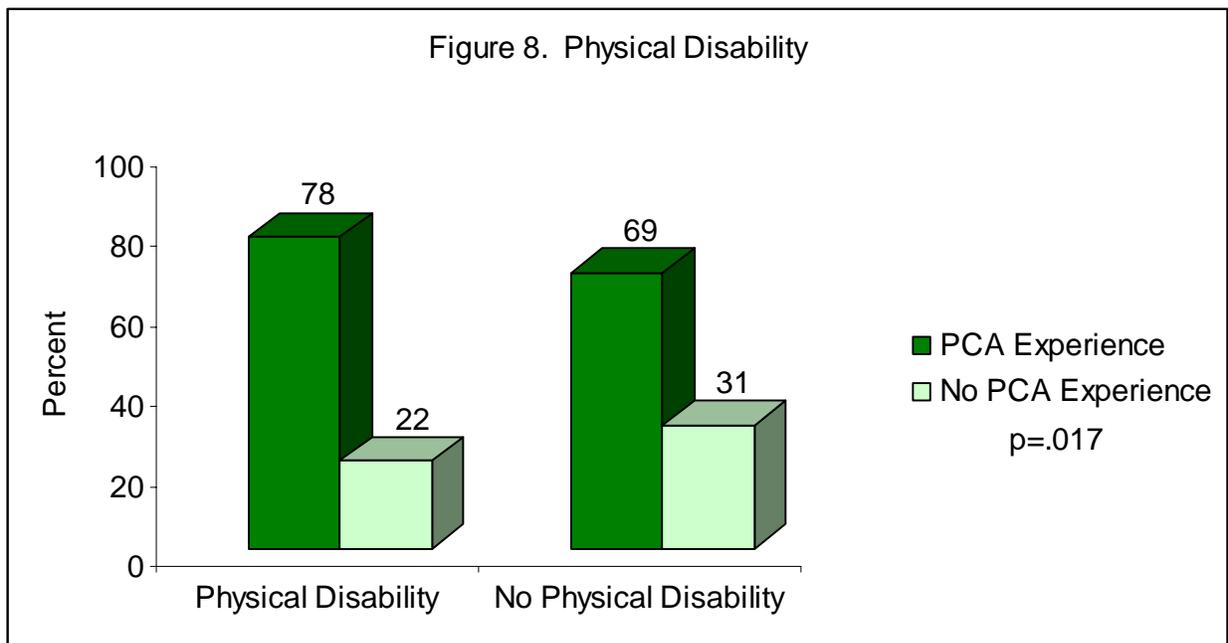


Figure 9. Intellectual Disability

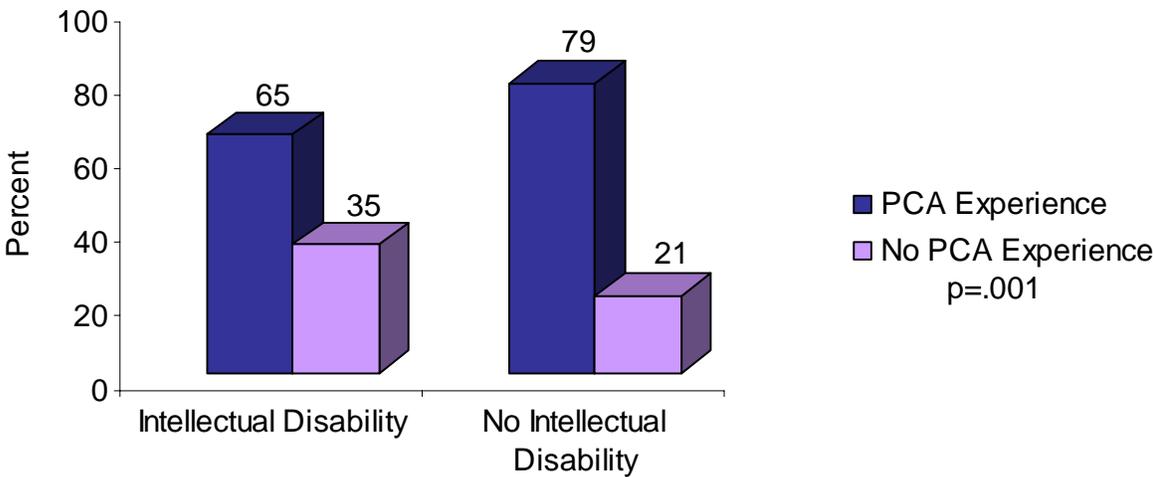
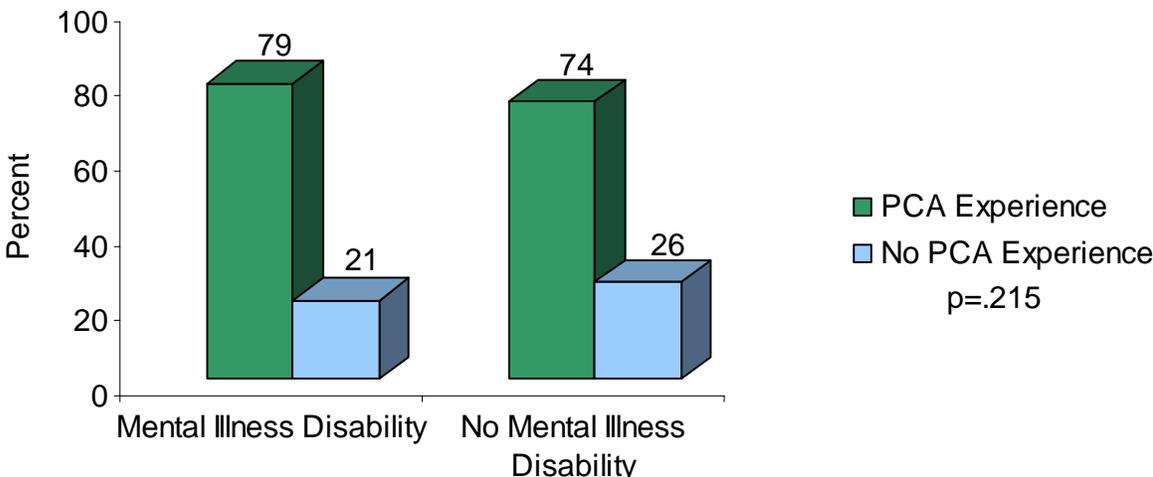
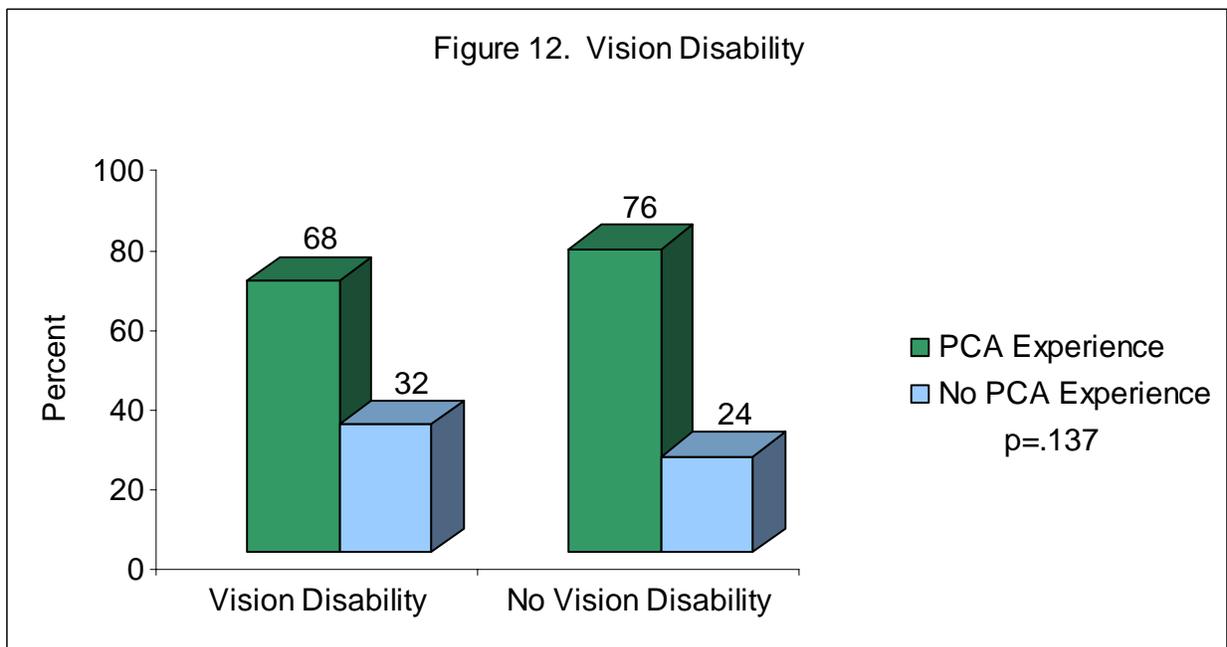
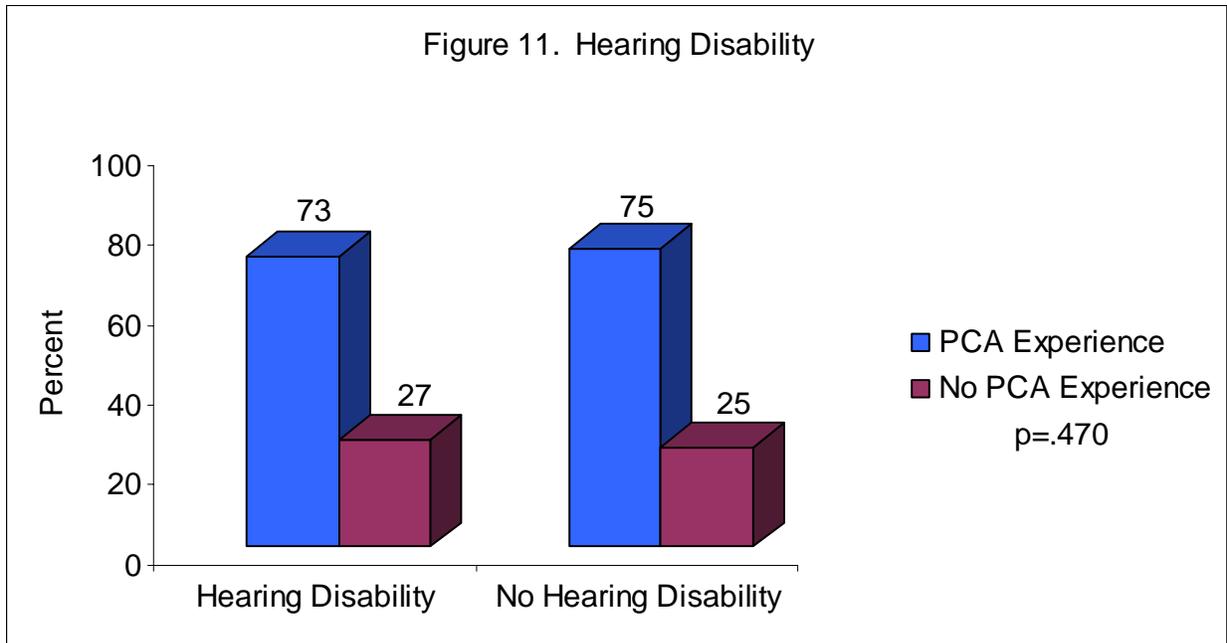
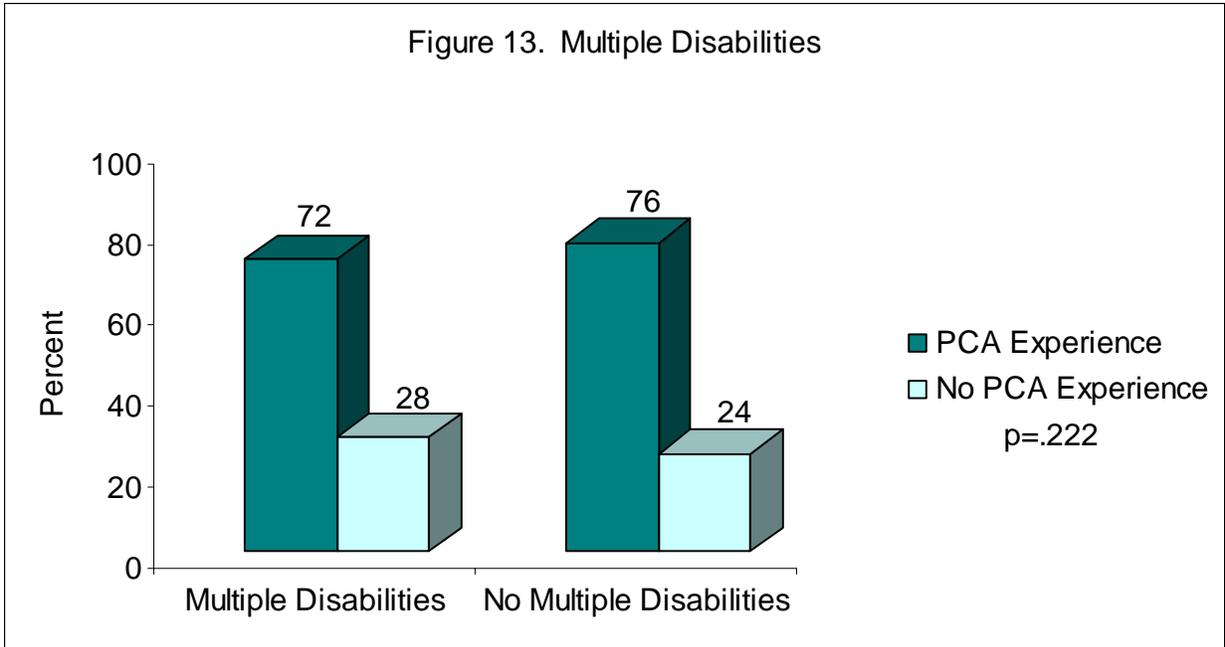


Figure 10. Mental Illness

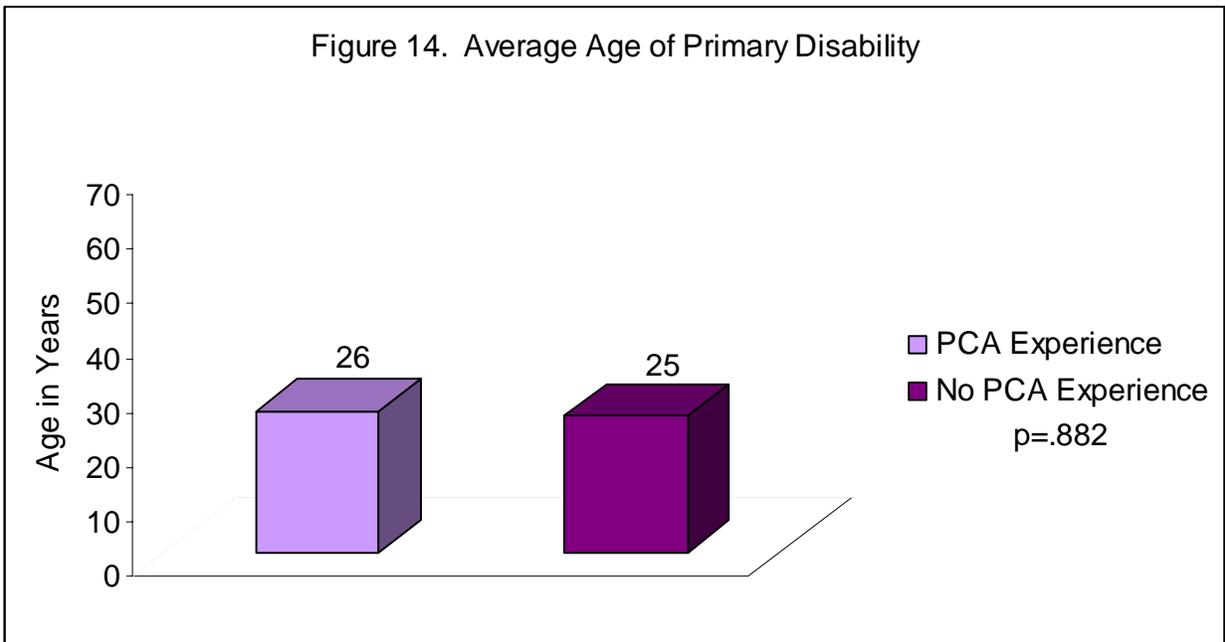


PCA experience is no more common for people with hearing or vision disability than for those without these disabilities (Figures 11 & 12). Finally, having multiple disabilities does not increase the likelihood of having a PCA (Figure 13).



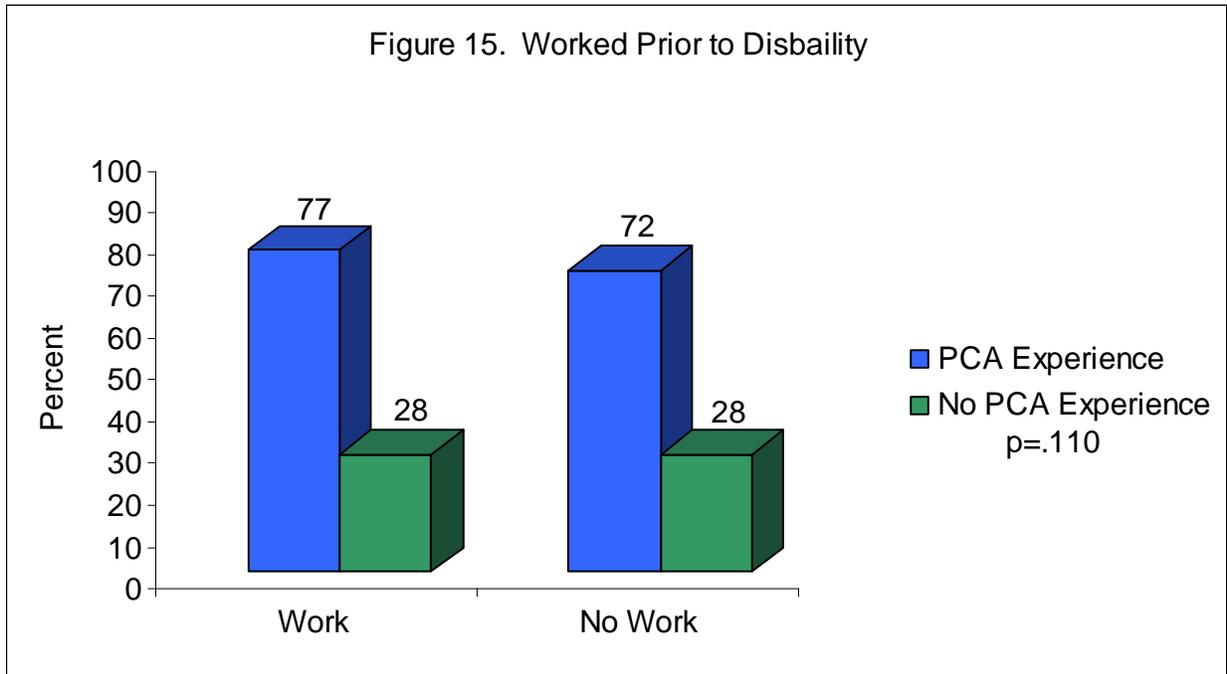


Average age of primary disability onset had no bearing on the use of personal assistants. Average age of disability onset of those reporting no PCA experience was 25 with a standard deviation of 23.3 years, and the average age of those reporting PCA experience was 26 with a standard deviation of 24.4 years (Figure 14).

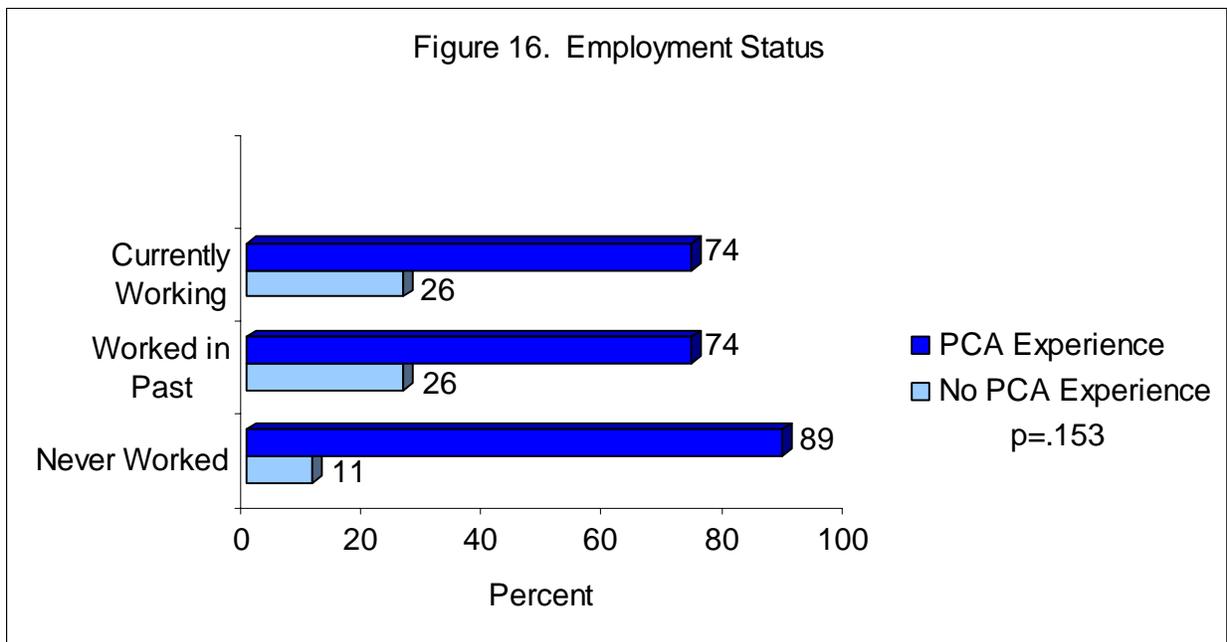


E. Work experience

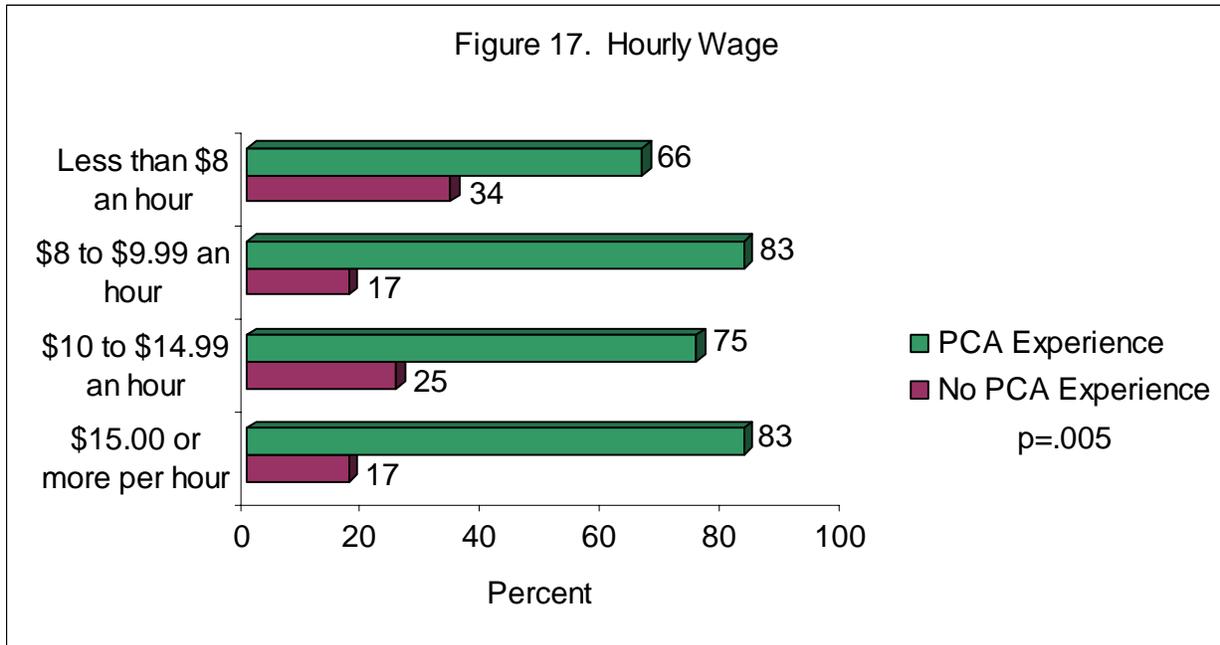
Analyses show that individuals who have worked prior to acquiring their disabilities are not more likely to have had a PCA than those who did not work previously (77% vs. 72%) (Figure 15).



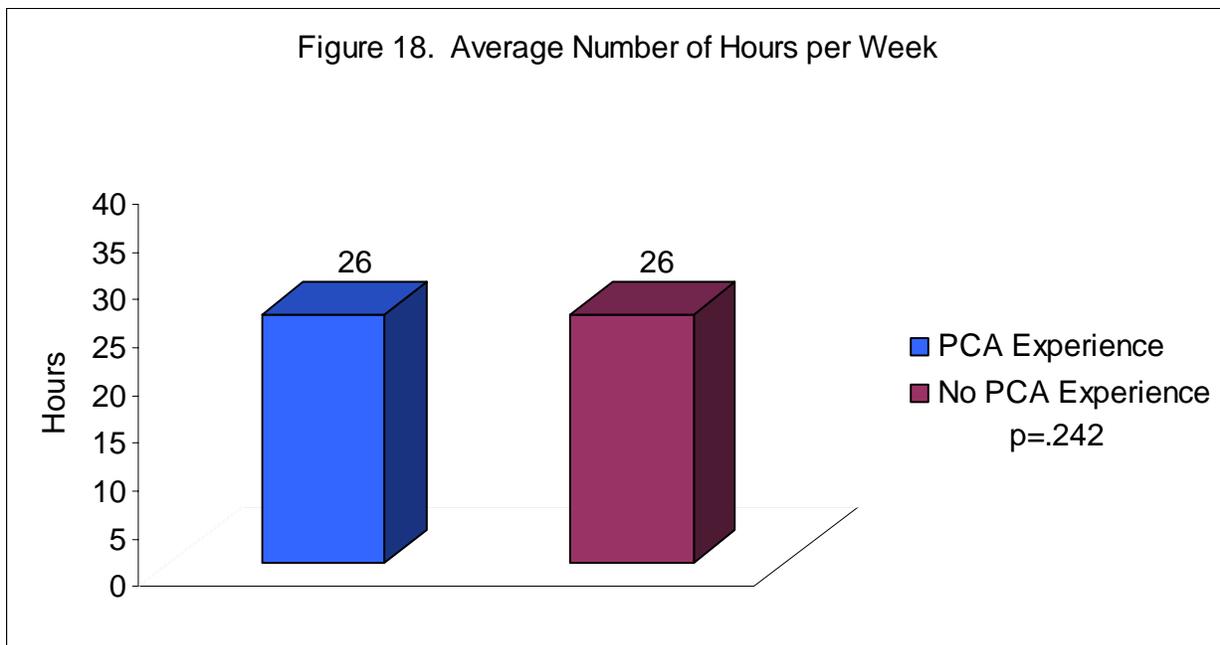
Though not statistically significant, there is a clear association between PCA experience and employment status. In absolute terms, individuals who report never worked, are 15 percent more likely to have PCA experience than those with a prior work history (Figure 16).



Personal Care Assistance experience does significantly vary by the amount of hourly wages. Those earning less than \$8 per hour are much less likely to have PCA experience (66%) compared to those earning \$8 to \$9.99 or \$15 or more (83%), while 75 percent of those earning \$10-\$14.99 had PCA experience (Figure 17).



However, there is no difference in the average number of hours worked per week for people who have had PCA experience versus those who have not; both groups work an average of 26 hours per week (Figure 18).



VI. VIGNETTE RESULTS

A. Understanding preferences for self-directed care

Vignettes have been widely used as a complementary technique alongside other methods of data collection and are a valuable tool for exploring people's beliefs and perceptions about specific situations (Finch, 1987). In order to better understand preferences for the self-directed care and management of community-based supports for people with disabilities, in-person interviews were conducted with nineteen (n=19) people with disabilities. In addition to completing interview questions that were identical to those used in the telephone interviews, vignettes were presented to elicit the attitudes of people with disabilities about the allocation of funds for personal services and supports. During the interview, each participant was given a copy of the three approaches to follow along with while the interviewer read the description of the scenarios out loud. Eighteen of the nineteen (95%) in-person respondents were able to complete the vignette section. The one respondent who could not was a 22 year old with non-physical disabilities. He/she had never had any need for these services and was not able to think hypothetically about it.

The three different approaches for administering services were modified from a model for consumer-directed community care developed by Sciegaj and colleagues (2004). In this study, Approach 1 represents the traditional provider agency model in which the provider agency talks with the individual about what types of assistance might be desired. The provider agency then decides what services and schedule the individual would receive and proceeds to find and purchase those services on their behalf. Approach 2 is a modified plan in which the individual and the personal manager or provider agency of their choice work together to determine what services and schedule are desired and then continue to work together to find and purchase these services. In Approach 3, the self-directed model, the individual would receive a monthly cash payment in order to manage their own services. In this approach the people with disabilities would receive advice and training to learn how to hire and fire, train, pay, and manage their paid assistant, and would be responsible for finding and purchasing desired services with the allocated cash payment.

Of the eighteen respondents to this question, half (n=9) chose Approach 2, the modified scenario in which they would work with a provider agency in helping to design a plan for hiring personal assistants. Three of the eighteen chose the self-directed model (Approach 3) and four chose the traditional provider agency model (Approach 1). Two of the participants indicated that they did not know which one to choose. It should be noted that some of the participants in the in-person interviews had never had any experience working with a personal assistant, so understanding the concept and making a choice was a challenge for them.

It's hard to tell. I had no experience with it. I'm clueless. I thought it was Step 1, Step 2, Step 3. Like this is what they're doing first, then this second, and then this one.

Among those who preferred Approach 1, the traditional agency model, there is an acknowledgement of the need to have direction and a degree of supervision.

Number 1: Because ... I need that guidance and would need that support. It would be easier to follow the rules to maintain that support. It would help my insecurity.

Chosen by half of the participants, Approach 2 seemed to be most popular because, as most of the participants agreed, they would need some help in one way or the other for some of the tasks involved in hiring a personal assistant. While they wanted to have some say in the service schedule and what services were provided and by whom, most of these respondents indicated that they would need some help or guidance in performing the other tasks, like hiring, training and paying the personal assistant.

Approach 2: Because you're working together on a budget with someone to help. Because I wanted help managing money, because I'm not good at that. I would have trouble hiring and training. It might be uncomfortable for me to do that.

Approach 2: I want to share the responsibility. That's a fair approach. It would take the pressure off of me to make all the decisions. We're both independent but help each other.

One of the participants felt that it would be possible to transition from Approach 2 to Approach 3.

I would want to start with Approach 2 because you and the agency would decide about it to guide me first. And then later, like 2 years later, maybe I could go to Approach 3.

With Approach 2 they know what to watch out for and how to do it. So I could learn from them first and then later go to Approach 3.

Some people with disabilities preferred the self-directed model because it helps them feel more independent and autonomous.

Approach 3: Because I get to hire this person. It's not appointed. With the money, I get to make my own choices and have the opportunity to oversee everything.

Approach 3: Because you're using your own skills and ability that you have. I think you should be able to do that.

While there is currently an emphasis on autonomy and self-directed care, findings from these in-person vignettes demonstrate a commonality with studies conducted in aging populations (Sciegaj et al., 2004). People with disabilities want to have some measure of control when it comes to hiring personal assistants and determining their service schedule, however, as was the case in this study, they also want agency support for the more challenging aspects of community-based care (i.e., paying and firing a personal assistant).

Based on the average time that it took for people with disabilities participating in this study to comprehend and respond to the three scenarios, it might be concluded that the presentation of the three scenarios is easily understood. The average time to respond, including the time for reading the three scenarios, was 4.5 minutes. The shortest time was 2-3 minutes, and the longest time was 10 minutes. Indeed, it might be feasible to do this type of a survey over the phone as the presentation of the three scenarios did not appear to be burdensome to the participants.

In sum, people with disabilities participating in this study indicate that independence and the experience of self-determination is valuable as is some degree of involvement in the administration of resources for their services and supports. Many also concurrently acknowledge the need for assistance with managing personal services and supports. Clearly, the best approach is one that is suited to their individual needs, their locus of control, and their ability to participate in the decision making process with regard to community-based long term care.

VII. Conclusions

The present study has certain limitations that need to be taken into account when considering the study and its contributions. The research design of the mail survey and telephone interview was a one-time survey that produced a profile of the characteristics of persons who have or do not have PAS experience. This type of cross-sectional design precludes being able to draw any conclusions about cause and effect relationships between characteristics. The second limitation has to do with the extent to which findings can be generalized beyond the cases studied. Some of the responses in certain categories were quite low and therefore cannot be expected to adequately reflect the properties of the larger population. For example, only four respondents without PCA experience indicated that they never worked versus 31 with PCA experience. Other categories, such as marital status, disability types (hearing and vision), and hourly wages (\$15 or more an hour) also had a low number of responses in some categories. A third limitation involves the difficulty in defining PCA across populations. Some respondents to the mail survey appeared to misunderstand the definition of PCA and indicated they had experience with a PCA when in fact they had agency-supplied home health aides. This confusion was evident from responses to open-ended questions, particularly in the CHCPE group. Thus, analyses for the survey responses were restricted to people under age 70 in this report.

Of particular interest in this study are those people who have experience with personal care assistants and the reasons for lower than expected numbers of people using support services. Historically, people with disabilities have been reluctant to accept help even when it's free and have needed to be persuaded to accept assistance for caregiving (Kane et al., 1998). However, data from these focus groups and key informant interviews indicate that those who have experience with PCA appreciate the support they receive at both home and work, but need help with recruiting and managing direct care workers. Although programs that provide PCA services are intended to promote independence and community integration, they are often not as user-friendly in the workplace (Hinton, 2003). It is projected that from 2005 to 2020, the population age 65 and older will increase by nearly half (50%) (Houser, Fox-Grage, & Gibson, 2006). As the baby boomer generation ages and the number of older workers rises, it is becoming increasingly important to address workplace policies and programs for people with disabilities. Approximately 58 million adults (34%) age 18 to 65 have at least one chronic condition and 19 million (11%) have two or more chronic conditions (Center on an Aging Society, 2004). Because employment is increasingly becoming a more important part of the lives of people with disabilities, it is critical to support this group in the workplace. It may involve amending medical eligibility requirements, approving new services or assistance, and developing a network of appropriate providers for employment. Iowa, for example, is exploring several policy issues including whether or not PCA access should be restricted to people who are able to commit to working a certain number of hours a month or if PCA services should be available in the workplace for only those who are able to hire and manage their own assistant (Hinton, 2003). Iowa is also considering an employee option to contribute pre-tax money to a

medical flexible spending account as part of a benefit package for PCA employment services (Hinton, 2003).

People with disabilities in the focus groups and key informant interviews also expressed concerns about family caregiving burden. This indicates that there is a need for more family-centered policies that take into account direct services to family caregivers (i.e., training programs and support groups), respite programs, and direct payment of family caregivers. While people needing supportive services often prefer to receive assistance from family and friends, the primary reason they do not seek paid assistive services is because they cannot afford them (Doty, 2004; Gibson, 2006; Mollica & Kassner, 2001). Providing more affordable paid services would support family members in their role as caregivers and help lessen unmet need among people with disabilities. Better insurance coverage for people with disabilities, especially for those ages 50-64 who aren't eligible for Medicaid or Medicare, would reduce their vulnerability to lack of services. Those that have authorized services are often at risk when care services aren't delivered and the burden of their care then shifts to family and friends. Clearly, state and local strategies are needed to ensure backup service delivery and provide monitoring. In order to provide greater HCBS services, rebalancing Medicaid long-term care programs is also necessary.

Data from focus groups and key informant interviews with providers indicate the need for better transitional services, more information and accommodations in the workplace for people with disabilities, increased disability education for employers, and more supports for employers who employ people with disabilities. Although PCA in the workplace are still in the formative stages, it is essential that people at the state level and employers work together to find ways to use public and private resources to offer a greater range of PCA for people with disabilities who want to work. In expanding efforts to include people with disabilities in the workplace, options might be for employers to provide services through a health insurance plan or medical flexible spending account, as is being done in Iowa (Hinton, 2003).

The survey results from this study show a significant association between the use of personal assistants and educational status: individuals who report more than a high school education are twice as likely to have a personal assistant than people with less than a high school education. Similarly, people in the lowest wage category have the lowest rate of PCA use. It should also be noted that while hourly wage was significant, annual income and number of hours do not impact PA experience. Lack of a clear pattern in hourly wage makes it difficult to draw conclusions that might explain PA experience and the variance by amount of hourly wages. Considerable efforts need to be made in developing service systems that increase care opportunities for those with less education and lower earnings. State efforts may need to incorporate system wide efforts to reach people in these groups who have significant long-term care needs. Most likely, primary mechanisms for identifying people in this group will need to take place through case management and providers at the local level.

Data from the survey indicate that two disability types largely predict the use of personal assistants: physical disabilities increase the likelihood of having a PCA, while intellectual disabilities decrease it. This suggests that there may be a greater need for screening, comprehensive assessment, care planning, implementation of the plan, monitoring, and reassessment of people with non-physical disabilities. Local case-management programs have an opportunity to serve as points of access for PCA because they conduct assessments, determine eligibility, and make suggestions related to the needs of consumers. It may be important to consider improved training and qualifications for case managers (e.g., accreditation

programs), and to develop employment initiatives that address the high turnover rate that currently exists among case managers in many state-wide programs.

Information from vignettes is useful for exploring people's beliefs, meanings, and perceptions. In this study, the purpose of using vignettes was to better understand preferences for the self-directed care and management of community-based supports for people with disabilities. It is clear that people with disabilities want to have some measure of control when it comes to hiring personal assistants and determining their service schedule, but they also value agency support for the more challenging aspects of community-based care, such as hiring and managing PCAs. It is also clear that there is a wide range of individual preferences and that a continuum of self-directed and agency-directed care needs to be available.

A number of recent publicly financed service initiatives have focused on consumer direction and indicate a growing interest in trying to control rising Medicaid long-term care costs by rebalancing public long-term care spending from institutional care to alternatives in the community (Spillman, Black, & Ormand, 2006). Subsequent to the Deficit Reduction Act signed in February 2006, this beneficiary-managed individual model, that had its origins in the Cash and Counseling Demonstration, has the potential to provide expanded HCBS. For example, this flexible service delivery model allows for the option of hiring nontraditional workers (e.g., family members and friends) and shows promise in helping increase the supply and reliability of long-term care workers. It also has the potential to promote better use of public funds while allowing people with disabilities to avoid institutional care. While Connecticut allows for self-direction through the Independence Plus waiver for the MR/DD population and for other small groups through the PCA, ABI and CHCPE pilot waiver groups, recommendations include continued efforts and implementation of similar services for people of all ages and disabilities. This would support ongoing initiatives for more publicly-funded consumer-directed HCBS.

In the future, state policymakers have the opportunity to expand consumer-directed models with flexible options that support people with disabilities in both home and work environments. With the right options and services, consumer direction can represent an important step forward in meeting the needs of people with disabilities in a way that respects their personal circumstances and preferences.

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IX. Appendices

Appendix A: Consumer Focus Group Questions

Appendix B: Provider Focus Group Questions

Appendix C: Consumer Key Informant Interview

Appendix D: Provider Key Informant Interview

Appendix E: Mail, Telephone, and In-person Interview Instruments Part II: PCA and Demographic Information

Appendix F: In-person Vignettes: Preferences for Level of Control in Consumer-directed Care

Appendix A: Consumer Focus Group Questions

[NAME OF ORGANIZATION] has entered into a strategic partnership through a grant with Connecticut's Medicaid Infrastructure Grant Steering Committee. This Steering Committee, made up of organizations representing Connecticut's public, private and educational sectors, seeks to improve the employment infrastructure within the State.

The purpose of the grant is to design an inclusive workplace for the future that will accommodate a diverse workforce including people with disabilities. The partnership offers the [ORGANIZATION] an opportunity to play an important role in this large systems change grant from the very beginning. Your input is very important to us in this process.

1. We are interested in learning about the transition from school to work, so we are starting with some questions about your school experiences. Think back about your experiences when you were in school – include high school, college, vocational school or anything else. Please describe the role your school played in preparing you for employment. [probe: were there specific people who helped, e.g., a guidance counselor?]
2. Please describe the role your parents played in preparing you for employment. [For example, did they encourage you to get a job or help you find a job?]
3. What do your family and friends think about you working? [Probe: do they feel you should be working more, working less, or not working at all? Has anyone ever advised you not to work?]
4. What prevents people with disabilities or special needs from getting the jobs that they want? [Probe: need for accommodations]
5. If you have had a job(s), or if you have looked for a job, how did you go about finding it/them? [Probe: what services, people or equipment assisted you in the search for your job?]
6. Which community-based programs or agencies helped you in your search for employment? [give examples of DMR, BRS if needed.]
7. Think about the existing service system that focuses on helping people with disabilities or special needs find and maintain employment.
 - 7a. What are its strengths?
 - 7b. What are its weaknesses?
 - 7c. What would you like to see more of?

8. If you had help from an agency or a community provider to look for a job, how did they learn about your interests and strengths? [Probe: To what extent were your interests and strengths matched to the jobs they recommended?]
9. If you work now or have worked, how much of your talents and skills do/did you use in your current or most recent job?
10. If you are working, what opportunities for advancement are there for you at your current company?
11. Please describe the supports or job accommodations you have used at work. [probe: what types of Assistive Technology, if any, have you used to perform your job?]
12. Please describe any experiences you have had with personal assistants or home health aides at a job.
13. If you could have had one additional thing in your life that would have better prepared you for employment, what would it have been? Is it too late to have it?

Ask the next set of questions if you have time. Select the questions most relevant to the group:

We have XX minutes left in our time today. I would like to ask the group just a few more questions that will be helpful to the project.

14. Outside your job, how do you participate in your community? [Probe – club member, recreation, church, volunteering]
15. If you feel that you would like to participate more in your community, what kind of supports would you need to do so?
16. Thinking back again to when you were in school, were you able to participate in extra-curricular activities as much as you wanted to? Please tell us more about that. [For Focus Group leader: we are trying to get at the system's capacity to include them and barriers they faced, not so much a list of activities: probe for positive and negative]
17. In school, were you able to participate in regular education classes as much as you wanted to?
18. What benefits are/were critical for you in choosing a job? (examples, health insurance, retirement, paid time off)

19. What difficulties have you/might you experience traveling to and from work?

Finish with this question:

20. Is there anything else you would like to add?

Appendix B: Provider Focus Group Questions

[NAME OF PROVIDER ORGANIZATION] has entered into a strategic partnership through a grant with Connecticut's Medicaid Infrastructure Grant Steering Committee. This Steering Committee, made up of organizations representing Connecticut's public, private and educational sectors, seeks to improve the employment infrastructure within the State.

The purpose of the grant is to design an inclusive workplace for the future that will accommodate a diverse workforce including people with disabilities. The partnership offers the [ORGANIZATION] an opportunity to play an important role in this large systems change grant from the very beginning. Your input is very important to us in this process.

1. What are the greatest barriers to people with disabilities who are looking for employment?
2. What do you see as the advantages to employers of hiring people with disabilities?
3. What are the greatest barriers to employers hiring people with disabilities?
4. Please describe your experiences working with potential employers of people with disabilities.
5. Which types of companies are the most accommodating to people with disabilities? (probe to consider size, industry, profit status, geographic location and other factors)
6. Think about the existing service system that focuses on helping people with disabilities find and maintain employment.
 - 6a. What are its strengths?
 - 6b. What are its weaknesses?
 - 6c. What would you like to see more of?
7. What are the most important programs or policies for the State of CT to implement?
8. Aside from your own organization, which other community-based programs or state agencies specifically related to employees with disabilities have you found useful?
9. What does the K-12 educational system do well to prepare people with disabilities for employment?
10. What does the K-12 educational system need to improve in order to prepare people with disabilities for employment?

11. How do you or your agency identify your clients' employment interests and strengths?
12. To what extent are people's employment interests and strengths matched to their job?
13. How important is Assistive Technology for your clients in terms of finding and keeping a job?
14. Describe the most creative situation, in helping someone achieve their employment goals, that you have ever been involved with.
15. How do attitudes of people with disabilities impact their success at finding and maintaining employment? (probe for negative and positive attitudes)
16. **Finish with this question:**
17. Is there anything else you would like to add?

Appendix C: Consumer Key Informant Interview

This interview is being conducted as part of a grant with Connecticut's Medicaid Infrastructure Grant Steering Committee. This Steering Committee, made up of organizations representing Connecticut's public, private and educational sectors, seeks to improve the employment infrastructure within the State.

The purpose of the grant is to design an inclusive workplace for the future that will accommodate a diverse workforce including people with disabilities. This interview is your opportunity to play an important role in this large systems change grant from the very beginning. Your input is very important to us in this process.

1. Think back about your experiences when you were in school – include high school, college, vocational school or anything else. Please describe the role your school played in preparing you for employment. [probe: were there specific people who helped, e.g., a guidance counselor?]
2. Please describe the role your parents played in preparing you for employment. [For example, did they encourage you to get a job or help you find a job?]
3. What do your family and friends think about you working? [Probe: do they feel you should be working more, working less, or not working at all? Has anyone ever advised you not to work?]
4. What prevents people with disabilities or special needs from getting the jobs that they want? [Probe: need for accommodations]
5. If you have had a job(s), or if you have looked for a job, how did you go about finding it/them? [Probe: what services, people or equipment assisted you in the search for your job?]
6. Which community-based programs or agencies helped you in your search for employment? [give examples of DMR, BRS if needed.]
7. Think about the existing service system that focuses on helping people with disabilities or special needs find and maintain employment.
 - 7a. What are its strengths?
 - 7b. What are its weaknesses?
 - 7c. What would you like to see more of?
8. If you had help from an agency or a community provider to look for a job, how did they learn about your interests and strengths? [Probe: To what extent were your interests and strengths matched to the jobs they recommended?]

9. What are your employment or career goals, what are you striving for?
10. What additional training or education do you need to achieve your goals?
11. If you work now or have worked, how much of your talents and skills do/did you use in your current or most recent job?
12. If you are working, what opportunities for advancement are there for you at your current company?
13. Please describe the supports or job accommodations you have used at work. [probe: what types of Assistive Technology, if any, have you used to perform your job? How did you get information on technology (what's available, how to use)? Who pays/paid for your technology?]
14. Do you require personal support, i.e., home health aides, personal assistants, etc.?
 - 14a. Approximately how many hours per week do they work with you, altogether? [if they
 - 14b. can't answer, ask in a typical day]
 - 14c. Would you need personal assistants or aides help you to get ready for work?
 - 14d. Would you need them to transport you to and from work?
 - 14e. Would they need to stay with you for part or all of your work day?
 - 14f. Do you have a backup plan if a personal assistant is very late or absent?
 - 14g. If you hire your own personal assistants, please describe the hiring process that has been most effective for you.
15. Have you ever been self-employed? [probe: If not, have you ever considered it? If yes but didn't do it, why not?]
16. What made you choose this path instead of working for someone else?
17. What were the advantages for you of self-employment?
18. What were the drawbacks?
19. Have you had any formal business training?

20. What support did you need to keep the business running?
21. Did you have access to this support?
22. If you could have had one additional thing in your life that would have better prepared you for employment, what would it have been? Is it too late to have it?

Ask the last questions if you have time. Select the questions most relevant to the person being interviewed:

We have XX minutes left in our time today. I would like to ask the group just a few more questions that will be helpful to the project.

23. Outside your job, how do you participate in your community? [Probe – club member, recreation, church, volunteering]
24. If you feel that you would like to participate more in your community, what kind of supports would you need to do so?
25. Thinking back again to when you were in school, were you able to participate in extra-curricular activities as much as you wanted to? Please tell us more about that. [For interviewer: we are trying to get at the system's capacity to include them and barriers they faced, not so much a list of activities: probe for positive and negative]
26. In school, were you able to participate in regular education classes as much as you wanted to?
27. What benefits are/were critical for you in choosing a job? (examples, health insurance, retirement, paid time off)
28. What difficulties have you/might you experience traveling to and from work?

Finish with this question:

29. Is there anything else you would like to add?

Appendix D: Provider Key Informant Interview

This interview is being conducted as part of a grant with Connecticut's Medicaid Infrastructure Grant Steering Committee. This Steering Committee, made up of organizations representing Connecticut's public, private and educational sectors, seeks to improve the employment infrastructure within the State.

The purpose of the grant is to design an inclusive workplace for the future that will accommodate a diverse workforce including people with disabilities. This interview is your opportunity to play an important role in this large systems change grant from the very beginning. Your input is very important to us in this process.

1. What are the greatest barriers to people with disabilities who are looking for employment?
2. What do you see as the advantages to employers of hiring people with disabilities?
3. What are the greatest barriers to employers hiring people with disabilities?
4. Please describe your experiences working with potential employers of people with disabilities.
5. Which types of companies are the most accommodating to people with disabilities? (probe to consider size, industry, profit status, geographic location and other factors)
6. Think about the existing service system that focuses on helping people with disabilities find and maintain employment.
 - 6a. What are its strengths?
 - 6b. What are its weaknesses?
 - 6c. What would you like to see more of?
7. What are the most important programs or policies for the State of CT to implement?
8. Aside from your own organization, which other community-based programs or state agencies specifically related to employees with disabilities have you found useful?
9. What does the K-12 educational system do well to prepare people with disabilities for employment?
10. What does the K-12 educational system need to improve in order to prepare people with disabilities for employment?

11. How do you or your agency identify your clients' employment interests and strengths?
12. To what extent are people's employment interests and strengths matched to their job?
13. How important is Assistive Technology for your clients in terms of finding and keeping a job?
14. Describe the most creative situation, in helping someone achieve their employment goals, that you have ever been involved with.
15. How do people with disabilities' attitudes impact their success at finding and maintaining employment? (probe for negative and positive attitudes)
16. Is there anything else you would like to add

Part II

This section is for everyone to fill out.

Please fill out this white form and one of the colored forms.

All responses are confidential.

Please check only one box per question, unless asked to do otherwise.

Management of a Paid Assistant or Helper

People sometimes employ someone to help them with tasks like personal care, mobility, or communication. This person could be a personal assistant, helper, or anyone else who is paid to help them at home or at work.

There are different ways for people to manage or work with their paid assistants or helpers. We would like to know how you would like to manage a paid assistant. **Even if you have not used a paid assistant or helper in the past, we are still interested in what you think.**

1. Who besides you should take part in the **finding and hiring** a paid assistant? Check all that apply.
 - Family or spouse
 - Friend or neighbor
 - Personal manager, case manager, or vocational specialist
 - State agency, such as DSS, BRS, DMR, DMHAS, etc.
 - Professional or provider agency, such as a home care agency, ARC, etc.
 - No one else besides me

2. Who besides you should take part in the **training and managing** of a paid assistant? Check all that apply.
 - Family or spouse
 - Friend or neighbor
 - Personal manager, case manager, or vocational specialist
 - State agency, such as DSS, BRS, DMR, DMHAS, etc.
 - Professional or provider agency, such as a home care agency, ARC, etc.
 - No one else besides me

3. Who besides you should take part in **making sure your assistant is paid**? Check all that apply.
 - Family or spouse
 - Friend or neighbor
 - Personal manager, case manager, or vocational specialist
 - State agency, such as DSS, BRS, DMR, DMHAS, etc.
 - Professional or provider agency, such as a home care agency, ARC, etc.
 - No one else besides me

4. Do you **currently** have any paid assistant or helper working for you?
- Yes, I currently have a paid assistant → **Go to Question 5, page 2**
 - No, I do not currently have a paid assistant, but I had one in the past → **Go to Question 10, page 3**
 - No, I never had a paid assistant → **Go to Question 16, page 3**

Currently Employing a Personal Assistant

If you do not currently have a paid personal assistant, go to Question 10, page 3

5. Overall, how satisfied are you with the quality of work provided to you by your paid assistant/s?
- Very satisfied
 - Somewhat satisfied
 - Somewhat dissatisfied
 - Very dissatisfied
6. How satisfied are you with the service schedule of your paid assistant, such as the day of the week and time of day?
- Very satisfied
 - Somewhat satisfied
 - Somewhat dissatisfied
 - Very dissatisfied
7. Do you need more paid personal help or assistance than you are currently receiving?
- No
 - Yes → Do you need more paid personal assistance at home, at work, or both?
 - At home only
 - At work only
 - Both at home and at work
8. Have you ever had any problems or hassles with any of your paid assistant/s or helper/s, either now or in the past?
- No
 - Yes → What problems or hassles have you had with your paid assistant/s?

9. Please mark one box for each statement showing how much you agree or disagree with each one: strongly agree, somewhat agree, somewhat disagree, or strongly disagree.

	Strongly agree	Somewhat Agree	Somewhat Disagree	Strongly disagree
I am sure I can find and hire the right paid assistant or helper for me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
If my paid assistant or helper is not doing a good job, I can talk directly with him/her about it.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
If my paid assistant or helper cannot come in that day, I can always find someone else to assist me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I can work out any disagreements I may have with my paid assistant or helper.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

If you **currently** have a paid personal assistant, go to **General Information, Page 5.**

Not Currently Employing a Personal Assistant

If you currently have a paid personal assistant, go to General Information, Page 5.

10. Have you ever had a paid assistant or helper working for you, even if it were for a short period of time?
- No → **Skip to Question 16**
 - Yes

11. When did your last paid assistant or helper stop working for you?
- Less than 6 months ago
 - 6 months to 1 year ago
 - More than one year ago

12. Why did your last paid assistant or helper stop working for you?

13. Overall, how satisfied were you with the quality of work provided to you by your last paid assistant/s?
- Very satisfied
 - Somewhat satisfied
 - Somewhat dissatisfied
 - Very dissatisfied

14. How satisfied were you with the service schedule of your last paid assistants, such as the day of the week and time of day?
- Very satisfied
 - Somewhat satisfied
 - Somewhat dissatisfied
 - Very dissatisfied

15. Did you ever have any problems or hassles with any of your paid assistants or helpers?
- No
 - Yes → What problems or hassles did you have with your paid assistants?

16. Would you like to have a paid personal assistant or helper at this time?
- No
 - Yes → Would you like help from a paid assistant at home, at work, or both?
 - At home only
 - At work only
 - Both at home and at work

17. Please mark one box for each statement showing how much you agree or disagree with each one: strongly agree, somewhat agree, somewhat disagree, or strongly disagree. It does not matter if you have had a paid assistant or not. Just answer how you think it would be to employ a paid assistant.

	Strongly agree	Somewhat Agree	Somewhat Disagree	Strongly disagree
I am sure I can find and hire the right paid assistant or helper for me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
If my paid assistant or helper is not doing a good job, I can talk directly with him/her about it.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
If my paid assistant or helper cannot come in that day, I can always find someone else to assist me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I can work out any disagreements I may have with my paid assistant or helper.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Please continue with General Information, page 5.

General Information

This section is for everyone to fill out.

All responses are confidential.

Please check only one box per question, unless asked to do otherwise.

Health

1. How would you rate your overall health at this time?
 Excellent
 Good
 Fair
 Poor

2. In the past year, have you needed assistance from another person with personal care at home, such as bathing, dressing, eating, or toileting?
 No
 Yes

3. In the past year, have you needed assistance from another person with personal care at work, such as eating or toileting?
 No
 Yes

4. In the past year, have you needed assistance from another person with activities such as cooking, housecleaning, laundry, errands, or shopping?
 No
 Yes

Housing

5. I am currently living... (Check only one.)
 By myself without any paid supervision or support
 With a spouse or other relatives
 With a live-in paid assistant
 With a friend or roommate without any paid supervision or support
 In a supervised living apartment or program
 In a transitional group home or halfway house
 In a community living arrangement or group home
 In a community training home (CTH or CTO)
 In a board and care home
 Other _____

6. Thinking about where you live, please mark one box for each statement showing how much you agree or disagree with each one: strongly agree, somewhat agree, somewhat disagree, or strongly disagree.

	Strongly Agree	Somewhat Agree	Somewhat disagree	Strongly disagree	
My neighborhood is safe.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
There is a city bus stop within easy access from where I live.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
I have a neighbor who is also my friend.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
I need more assistive technology or devices in order to easily live in my home.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
I need more home modifications or changes in order to easily live in my home.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
There is a grocery store within easy access of where I live.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
I would like more privacy where I live.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
I get along well with the people I live with.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> I live alone

7. Were there any times in the past 12 months when you did not have enough money to: (Check all that apply.)
- Pay rent, mortgage, or real estate taxes
 - Pay utility bills (heat, electricity, phone)
 - Pay more than the minimum balance due on a credit card
 - Purchase or repair a car or van
 - Pay for medical or health care
 - Buy needed food
 - Pay for child care
 - Pay for anything else _____

Transportation

8. How do you usually get to places out of walking distance? This can include going to work or getting to any other activities you do on a regular basis. Check all that apply.
- I drive myself in my own car or van
 - Someone else drives me in my car or van
 - I get a ride from another person in his/her car
 - I use public transportation such as a city bus
 - I use the group home or day program van
 - I use dial a ride, a handicapped van, or para-transit
 - I use a taxi service
 - Other _____

9. What transportation difficulties have you had in the past 12 months? Check all that apply.
- The car I use is not always available or needs repairs.
 - I do not always have access to a lift van.
 - Public buses are not always available or are difficult to use.
 - The dial-a-ride, handicapped van, or other transportation I use is not always available.
 - It costs too much.
 - The van or bus will not take me to all the places I need to go.
 - A person is not always available to assist or to drive me.
 - Other _____

General Information

10. What is your age? _____
11. What is your gender?
- Male
 - Female
12. What is your marital status?
- Married
 - Widowed
 - Divorced or Separated
 - Single, never married
 - Living together as though married or had a civil union
13. What is the highest grade or year you finished in school?
- 8th grade or less
 - Some high school
 - High school diploma or GED
 - Post high school other than college
 - Some college or two year degree
 - Four year college degree
 - More than four year college degree
14. Which category best describes your race?
- White or Caucasian
 - Black or African-American
 - Asian, including Asian Indian, Chinese, Filipino, Korean, Vietnamese, or other Asian
 - American Indian or Alaska Native
 - Native Hawaiian, Samoan, or other Pacific Islander
 - Other (write in) _____
15. Are you of Spanish, Latino, or Hispanic origin?
- No
 - Yes

16. What language do you mainly speak at home?
- English
 - Spanish
 - Other _____
17. What is your total family income from all sources before taxes? We are not interested in your exact income, just the income category you fit into.
- Under \$10,000
 - \$10,000 to under \$25,000
 - \$25,000 to under \$50,000
 - \$50,000 or more
18. Who filled out this survey? Please list everyone who filled out this survey. Do not put in anyone's name. Instead, check the box describing that person's relationship to the client who this survey is about. Check all that apply.
- Client who this survey is about
 - Spouse or partner of client
 - Parent of client
 - Other relative of client
 - Friend of client
 - Personal assistant or other paid helper of client
 - Case worker or manager of client
 - Vocational counselor of client
 - Other (list relationship to client): _____

**Thank you for taking the time to participate in this survey.
Please mail your completed survey in the postage paid,
self-addressed envelope provided.**

Appendix F: In-person Vignettes: Preferences for Level of Control in Consumer-directed Care

Preferences for level of control in the organization, planning and management in consumer-directed care. In-person interviews only.

We'd like to talk with you about paid personal help or assistance. People sometimes employ someone to help them with tasks like personal care, mobility, or communication. This person could be a personal assistant, helper, or anyone else who is paid to help them at home or at work.

There are different ways for people to manage or work with their paid assistants or helpers. Managing a paid assistant can include finding someone, training them, deciding on a work schedule, and paying them. I'm going to read you three different approaches or ways a person could manage their personal assistants, and then ask you what you think about them. **Even if you have not used a paid assistant or helper in the past, we are still interested in what you think.**

Hand the respondent the Green Approaches Sheet with the three approaches on it, so he/she can read along with the interviewer.

Approach 1

In Approach 1, you and a provider agency talk about what assistance or help you would want from a paid assistant. The provider agency then decides what services and schedule you will get. The agency then finds and purchases the services for you.

Approach 2

In Approach 2, you are given a set budget based on your needs. Together with the personal manager or provider agency of your choice, you decide what services and what schedule you want. You and the provider agency or personal manager work together to find and purchase these services.

Approach 3

In Approach 3, you receive a monthly cash payment for you to hire and manage your own services. In this approach you can also get advice and training to learn how to hire and fire, train, pay, and manage your worker. You would be responsible for finding and purchasing any services you need with the cash payment you are given.

1. Which approach do you like the best? Can you tell me more about that? What do you like about that approach? Why do you like it better than the other ways a person can find and manage a paid assistant?
