ABSTRACT

WHAT MATTERS MOST: PASSPORT HOME CARE AIDES’ VIEWS ON OHIO’S INITIAL STEPS TO IMPLEMENT PERSON-CENTERED CARE

by Heather M. Nelson

The purpose of this research was to document the experiences of the PASSPORT home care aides in using What Matters Most: A Guide for my Support and Care (WMM) developed by Scripps Gerontology Center. The WMM Guide, pilot-tested in southern Ohio, provides a formal structure to document a consumer’s needs, strengths, goals and service preferences. Data were collected through semi-structured interviews with seven home care aides. Findings revealed that all of the home care aides found value in the information, especially if the WMM Guide is received prior to the start of services. Second, while they were not familiar with person-centered care terminology, they all described an approach to care that is consistent with person-centeredness. Third, provider level buy-in for person-centered care, supported through training and policy change, will be essential to the success of this initiative.
WHAT MATTERS MOST: PASSPORT HOME CARE AIDES’ VIEWS ON OHIO’S INITIAL STEPS TO IMPLEMENT PERSON-CENTERED CARE

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Background

For nearly fifty years, the aging enterprise has not been particularly person-centered, but service-centered. States are now scrambling to put systems in place to meet new federal guidelines under Sections 2402(a) of the Affordable Care Act (ACA) of 2010 and the Centers for Medicare and Medicaid Services under section 1915(c) and 1915(i). These new policies require states receiving federal funding for their home and community-based long-term services (HCBS) to use sometimes limited resources to provide person-centered and consumer directed care for older adults and disabled individuals to maximize their choice and independence while living in the least-restrictive environment of their choice. This act also requires states to use a more consistent and coordinated approach to the development of state rules, regulations, policies and procedures across home and community based Medicaid waiver programs regardless of the populations they serve (Health and Human Services [HHS], 2014).

The PASSPORT (PSP) program is Ohio’s home and community based Medicaid waiver program for adults over sixty years old who meet a nursing facility level of care and are Medicaid eligible. The Ohio Department of Aging (ODA) and the Ohio Department of Medicaid (ODOM) administer the PSP program through formal agreements with 13 PASSPORT administrative agencies (PAAs) that serve all 88 counties in Ohio. In 2011, PAAs provided PSP services for nearly 30,000 program participants. PSP program assessors and care managers employed by the PAAs are responsible for completing a comprehensive assessment and developing and implementing a service plan for all PSP consumers (Mehdizadeh, Applebaum, Nelson, Straker & Deacon, 2013).

In an effort to meet the new federal rules for Ohio, the PSP program has undertaken a significant step forward in providing person-centered care. The What Matters Most: A Guide for My Support and Care (WMM Guide) developed by researchers at Scripps Gerontology Center provides a formal structure to obtain and document a consumer’s needs, strengths, goals and service preferences. Funded partially by ODA, this guide will be used by PSP care managers to gather information directly from PSP consumers about who they are and how they like to spend their day and with whom, their current social support and how this can be strengthened, how the PSP program can help them meet their goals for their daily life and future, and service preferences about their household and personal care. This information will be transmitted to the contracted PSP home care provider that assists the consumers with their homemaker and
personal care services. The nurse supervisor will work directly with the home care aides (HCAs) to ensure that the PSP consumers’ stated preferences are heard and their preferences and expectations are met to the extent possible. This guide was piloted in the months of October 2014 through January 2015 with Area Agency on Aging District 7’s (AAA7) PSP care managers and their contracted home care agencies in the five southern Ohio counties of Adams, Brown, Highland, Lawrence and Scioto.

This study documents the experiences of the home care aides in using the *WMM Guide*; of particular interest is how it impacted their work and relationships with their nurse supervisors and consumers. The home care aides in this study provide personal care and homemaking services for PSP consumers in their home environment.

**Research Objectives**

1. Understand how (if at all) the information in the *WMM Guide* impacted the home care aides’ relationships with the consumers they served: how they viewed them and how they tried to meet their service preferences.
2. Understand how (if at all) the *WMM Guide* was shared with the home care aides, training they received and how the guide may have changed the way agency staff (nurse supervisor/scheduler/HCA) communicated and supported each other.
3. Document any recommendations the HCAs have on the content, structure and process logistics for the *WMM Guide*.

It is important to provide the home care aides the opportunity to contribute to the effectiveness of the person-centered initiative. Home care aides have more contact with PSP consumers than any other formal supports involved in their care. Without the support from the home care aides, person-centered planning cannot reach its potential within the current service-planning model. It is important to ask their input not only on the content, structure and process logistics for using the *WMM Guide*, but their thoughts on providing person-centered care within the PSP program structure.
Literature Review

Despite the positive intentions of the Older Americans Act passed in 1965, the aging enterprise has acted upon the social construction of aging that defines older adults as a social problem to society, and the solution to the problem is providing services to them and their families (Estes, 1993). Over the last thirty years, as states have developed and funded programs, such as PASSPORT in an effort to keep older adults in their home environment and out of institutions, this service-centered model has prevailed. A shift is occurring in the aging enterprise to move to a more person-centered system. It is difficult to pinpoint exactly when and where this new person-centered policy began, but pieces of it are found in all branches of the federal government: the executive (e.g., ACA), the legislative (e.g., OBRA ’87) and the judicial (e.g., Olmstead v. L.C.) branches. This literature review will first, describe how federal policy is changing towards requiring states to have a person-centered home and community based aging system; second, what person-centered care looks like in practice, and finally, what this policy change potentially means for those providing direct care for older adults and their families.

Change is a Constant

As the aging network reaches its 50th anniversary, the aging enterprise is finding itself in a state of constant change due to shrinking budgets and increased competition while trying to meet the service needs of our growing aging and disabled populations who may have higher service expectations than previous cohorts. The recent creation of The Administration for Community Living (ACL) brings together in a single entity the Administration on Aging (AOA), the Office on Disability, and the Administration on Developmental Disabilities (Notarstefano, 2012). Combining these populations under the same umbrella organization at the federal level is creating some challenges and opportunities for aging services across the United States. However, whether an individual has had to cope with a disability life-long or is recently diagnosed with a disability due to advanced age does not change their desire to age successfully while receiving publicly funded services. While these individuals may not have avoided disease and disability, they still want to continue to age successfully by remaining “engaged in life” and as independent as they can be (Young, Frick & Phelan, 2009).

There are three landmark federal policies that are contributing to many changes to the long-term care system serving individuals of all ages with physical and mental disabilities in the
United States (Bishop & Stone, 2014). First, is the Omnibus Budget Reconciliation Act of 1987 (OBRA ‘87) that tightened federal minimum standards in Medicare and Medicaid funded nursing homes. This legislation led to a national “culture change” movement in an effort to enhance the residents’ quality of care, quality of life, and enhanced residents’ rights (Bishop & Stone, 2014; Centers for Medicare and Medicaid Services, 2012; Weiner, 2003). Second, is the Supreme Court’s 1999 decision in Olmstead v. L.C. that gave mentally and physically disabled individuals the right to live in the least restrictive environment of their choice if they are able (Kaye & Harrington, 2014). Third, in 2010, the Patient Protection and Affordable Healthcare Act (ACA) included a number of new provisions that require states to provide person-centered care and include funding incentives to increase access to home and community-based services for older and disabled adults (Kaye & Harrington, 2014).

Today’s policy roots of recommending patient-centered care to improve quality and outcomes can also be traced back to the 2001 release of the report Crossing the Quality Chasm: A New Health System for the 21st Century, by the Institute of Medicine’s (IOM) Committee on Quality of Health Care. This report helped to raise the awareness of the poor quality, racial and social economic disparities, and rising costs of the current health care system in the United States. This report started the dialog of providing more patient-centered care when it was included as one of the six dimensions that the committee recommended to improve the health care system in the United States to meet patient needs (Berwick, 2002; IOM, 2001a; Lusk & Fater, 2013; Shaller, 2007). The Institute of Medicine (2001b) defined patient centeredness as:

Health care that establishes a partnership among practitioners, patients, and their families (when appropriate) to ensure that decisions respect patients' wants, needs, and preferences and that patients have the education and support they need to make decisions and participate in their own care. (p. 7)

Less than ten years after the IOM’s recommendations, federal policies such as the Affordable Care Act (ACA) of 2010, are mandating person-centered care within all state home and community based Medicaid waivers. This language has been used in the disability community for 35 years and more recently in nursing facilities implementing culture change, but is relatively new to home and community based Medicaid waiver programs (O’Brien & O’Brien, 2000). For the disability community, person-centered approaches had common themes of
“increasing choice, advocating de-personalizing labels and difference-making procedures, honoring the voices of the person and those who know the person best, building relationships, individualizing supports based on high expectations, and demanding that agencies adopt new forms of services” (O’Brien & O’Brien, 2000, p. 16).

Under the Affordable Healthcare Act, Ohio has applied for increased federal Medicaid funding under the Balancing Incentives Payment Program. This program provides incentives to states to provide long-term care supports in the home and community in an effort to reduce Medicare and Medicaid costs on institutional care. Ohio is working towards significant system reform such as the development of a single point of entry for all home and community based services, conflict-free case management, and the development of one assessment tool and management information system (Patton, 2013). Another purpose for the Balancing Incentives Payment Program is to “Improve systems performance and efficiency, create tools to facilitate person-centered assessment and care-planning, and enhance quality measurement and oversight” (Donica, 2012, p. 2). WMM Guide is one of the first tools developed that will directly help Ohio meet the Balancing Incentives Payment Program requirement to facilitate person-centered assessment and care planning.

**Person-centered Care in Practice**

Research, direct practice, and education in aging have long brought together a diverse group of people with different educational backgrounds to help solve complex problems facing older adults and their families (Skinner, 2001; Stone & Harahan, 2010). Our long-term care system brings together a multidisciplinary team of nurses, aides, social workers, therapists, researchers and physicians. Each discipline brings with it their core professional beliefs, such as ethics. Federal guidelines are now requiring this multidisciplinary team to work together and include clients and their caregivers in the development of their “person-centered service plan.” The clients must help to “identify the services and supports that are necessary to meet the person’s identified needs, preferences, and quality of life goals” (Health and Human Services [HHS], 2014, p. 6).

Defining person-centered care and developing new policies is easier than formalizing a new approach to implement person-centered care in home and community based Medicaid programs. This is a paradigm shift in aging from a medical assessment and task oriented care planning model to a more person-centered care assessment and care planning model (Ronch,
2003). This paradigm shift has been more prevalent in the “culture change” movement in institutional settings, such as in assisted living and nursing facilities (Simmons & Rahman, 2014). Since the passing of OBRA ’87, the Centers for Medicare and Medicaid Services (CMS) have helped lead the way to improve the quality of care in institutional settings by promoting person-centered care (CMS, 2012). Now CMS is changing their focus from institutional care to home and community based Medicaid programs.

In a nursing facility setting, the multidisciplinary team comes together every 90 days to discuss each resident’s medical and psychosocial needs. All team members have pieces of the Minimum Data Set (MDS) and residents and their caregivers should be involved in this process. For home and community based programs, such as PSP Medicaid and Medicare skilled home care services each member of the multidisciplinary team is on their own island and rarely do they come together to discuss a PSP consumer’s medical and psychosocial needs as a team. A PSP consumer not only has multiple services and professionals coming into their home, but also for every home and community-based long-term care service, they may have a different provider. It is currently a fragmented care process and this makes implementing a person-centered care assessment and care planning model more challenging than when the client and the multidisciplinary team is under one roof and sees each other daily, such as in a nursing facility.

In nursing facilities, tools such as the Minimum Data Set (MDS), Preferences for Everyday Living Inventory (PELI), and the PCC toolkit developed for Advancing Excellence in America’s Nursing Homes have been developed to gather and document residents’ preferences for their care (CMS, 2012; Simmons & Rahman, 2014; Van Haitsma et al., 2012). According to Simmons and Rahman (2014), even with these tools in nursing facilities, there are many barriers to providing person-centered care and for home and community based programs some of these barriers are more challenging.

First, Simmons and Rahman (2014) point out the importance of staff offering residents “choices” with every care interaction, such as when they want to go to bed or what they want to eat. They have developed training modules and tools to help nurse supervisors observe and document interactions with direct care staff and residents. After evaluating this process at multiple nursing facilities, they report that while residents expressed being given a choice was important to them, staff did not often provide residents with choices for their care when observed. The second barrier includes multiple staffing issues: (1) deciding who will be
responsible for completing the initial and follow-up interviews and assessments with residents; (2) deciding who will be responsible for reviewing and updating these tools; (3) deciding who will ensure staff are carrying out resident preferences. Staffing issues can be even more challenging in facilities where there is high staff turnover, poor staff to resident ratios and there is little buy-in by staff. The third barrier is while care conferences are held every 90 days, often the nurse aides are not present. If the direct care staff is not there to hear the strategies proposed to meet the resident’s care preferences they potentially will not be carried out (Simmons & Rahman, 2014). As Simmons & Rahman (2014) conclude, the tools that are being developed are a great start, but next steps need to include “specific strategies related to who completes the interviews and assessments, how often interviews and assessments are completed, and, most importantly, what should the facilities do with the information once it is collected” (p 618).

Impact of Person-centered Care on Direct Care Staff

The demand for direct care workers, such as home care aides, is growing exponentially. Nearly five million direct care workers will be needed to meet the demands of caring for our older and disabled adults in the United States by 2020 (PHI, 2013). Along with informal family caregivers, formal direct care workers are the backbone of our long-term care system. The growing need for formal caregiving services is not only due to our aging population, but is being impacted by the changes in American families, such as divorce, smaller families, and family members living in different geographic locations (Butler, Wardamsky, & Brennan-Ing, 2012). Providing direct care to older adults in any setting is physically, emotionally, spiritually and mentally taxing (Diamond, 1992; Mittal, Rosen, & Leana, 2009). Traditionally, predominately older women and women of color make up our direct care workforce. This work is generally part-time, low pay and with limited benefits and turnover is very common. Turnover not only affects quality of care, but drives up the cost due to the ongoing need to hire and train qualified staff (Butler et al., 2012).

Previous research has shown that turnover was lower in nursing facilities where certified nursing assistants were invited to participate in care conferences (Banaszak-Holl & Hines, 1996). Mittal, Rosen and Leana (2009) conducted focus groups with direct care workers and found that a “lack of respect” from management, such as nurse supervisors, was a leading cause of turnover among direct care workers. Another theme that emerged from the authors’ focus groups is that
while pay and benefits were low, the participants felt they were being “called” to this type of work and saw themselves in an advocacy role even though their work had so many challenges.

In 2013, the U.S. Department of Labor (DOL) mandated that beginning January 1, 2015, most home care workers would be guaranteed federal minimum wage and overtime protections for the first time. After pressure from states who were concerned about the extra costs, the DOL announced that it would not enforce the new rule for the first six months of 2015 (Greenhouse, 2014). If policy makers are not able to offer a living wage with benefits, how are we going to entice good qualified individuals into these fields to meet the caregiving needs of disabled and older adults? The aging enterprise can create all the tools it can to capture a client’s needs, strengths, goals and service preferences, but if we do not have caring and qualified staff to carry out the strategies to implement these preferences unsupervised it is wasted time and paper. Previous research has shown that in order to satisfy customers, the place to start is satisfied employees (Rave et al., 2003). As Shaller (2007) states:

If health care organizations want to become patient-centered, they must create and nurture an environment in which their most important asset—their workforce—is valued and treated with the same level of dignity and respect that the organization expects its employees to provide to patients and families. (p. 11)

In summary, this pilot study tests Ohio’s first steps in implementing person-centered care within the PSP program using the WMM Guide. Will implementing person-centered care within the PSP program empower the home care aides to see how vital they are to providing quality of life and quality of care in our long-term care system and impact turnover (Mittal et al., 2009; Stone & Harahan, 2010)? Even more importantly, how can nurse supervisors, care managers, and nurse aides work together to help PSP consumers get the most out of their services and meet their PSP program goals and to live a better and more enriched life? Policy makers cannot expect the aging enterprise to change systems that were developed over the last fifty years overnight. However, with small steps this paradigm shift to person-centered care may have more of a positive impact on older adults and those who care for them than we ever imagined.
Design and Methods

Pilot Study Procedures

The WMM Guide was piloted in the months of October 2014 through January 2015 with AAA7’s PSP care managers and their contracted home care agencies in the five southern Ohio counties of Adams, Brown, Highland, Lawrence and Scioto. The WMM Guide provides a formal structure for the care manager to obtain and document a consumer’s needs, strengths, goals and service preferences (Appendix A includes the WMM Guide framework and sample questions). For the full pilot study, WMM Guides were completed with forty recently enrolled PSP consumers in the five southern Ohio counties. At the outset of the overall pilot project, the WMM Guide was determined to be a case management tool that would be communicated to the provider agency supervisors. Because of the way the PSP system was designed, care managers typically make their initial visit to consumers after services have started. PSP care managers have thirty days to complete a home visit with newly enrolled PSP consumers after home care services have started. Decisions about how the information would be transmitted to home care aides by their supervisors were left to the discretion of the agencies. The way that process unfolded was one of the research questions for the overall pilot project. However, it has implications for this project focused on home care workers, as will be seen in the questions and findings from this study. The complicated process for collecting and transmitting WMM Guide information is shown in Appendix B.

Seven PSP care managers participated in this pilot study; they completed the WMM Guide at their initial visits with PSP consumers. The PSP care managers then faxed the WMM Guide to the contracted PSP agency that was already providing services for the PSP consumer. The WMM Guide was to be reviewed by the scheduler, nurse supervisor and the home care aide. The home care aide was to take the WMM Guide to their PSP consumer’s home, review it with them and leave a copy of the WMM Guide where the PSP consumer designated, such as on the refrigerator or in the provider’s folder.

Twenty-seven AAA7’s contracted PSP agencies had attended a training that included an overview of person-centered practice, role playing activities with the WMM Guide, and group discussions to help inform Scripps researchers on the use of the WMM Guide in direct practice. All twenty-seven AAA7’s contracted PSP agencies that attended the training were eligible to receive the WMM Guides to use with their staff and PSP consumers during the pilot. In addition
to this study, as part of the *WMM Guide*’s pilot evaluation the Scripps research team conducted focus groups and key informant interviews with administrative staff at the home health agencies and PSP staff from AAA7.

**Participating Home Health Agencies**

At the end of the pilot study, fifteen of the twenty-seven agencies had received between one and seven of the completed *WMM Guides* to use with their PSP consumers across the five counties. Distribution of the *WMM Guides* to the fifteen home health agencies can been found in the table below:

Table 1. Distribution of WMM Guides across 15 Home Care Agencies in Pilot Study

<table>
<thead>
<tr>
<th>Agency</th>
<th>Number of Guides Received</th>
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<tr>
<td>1</td>
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<td>16</td>
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**Recruitment**

For this current study focused on home care aides, letters were mailed to agency one, three, five, seven, eight and nine targeting those that received the most *WMM Guides* and the agency’s geographic location (Appendix C includes the recruitment letter). These agencies were then contacted by telephone and if necessary by e-mail. Three out of the six agencies arranged one-on-one interviews with the home care aides who were working with PSP consumers where their PSP care managers completed the *WMM Guide* with them. Home care aides were asked to participate in one 60-minute (maximum) interview that was conducted in a private conference room at their agency of employment. Each home care aide received $20.00 cash as compensation.
for their time and any mileage. The home care aides provided signed consent prior to starting the interview (Appendix D includes the participant consent form).

Data Collection

Data from interviews was collected during January and February of 2015 after the larger pilot study ended. Semi-structured face-to-face interviews were conducted with seven home care aides who worked at three home health agencies. A structured interview guide was created, but as interviews took place, other thoughts were encouraged if they were appropriate to the use of the WMM Guide. Interviews covered topics regarding how their nurse supervisor shared the WMM Guide with them, how new information impacted how they saw the PSP consumer they help, how the new information impacted their work with the PASSPORT consumer, and their recommendations on the WMM Guide’s content, structure and process logistics (Appendix E includes the interview guide). Interviews were taped and concurrent field notes were taken on the interview guide (Halcomb & Davidson, 2006). Home care aides were asked to check on the interview guide the most appropriate answers for their demographic information, such as age, race and education. Interviews were later reviewed and responses were recorded on a Microsoft excel table for analysis. The Microsoft excel table was arranged as the data occurred on the interview guide. For instance, the top columns were titled: (1) Agency name; (2) Initials of participants; (3) Participant’s gender; (4) Date of interview; (5) Start time of interview; (6) End time of interview; (7) all 16 questions had a column; (8) Other column. The data from each interview was recorded on its own row. Direct quotes were transcribed for each question, as appropriate.

It was necessary to obtain approval for this study from Miami University’s Institutional Review Board. This study was considered exempt; the IRB exempt research certificate number is 01472e.

Results

Sample Description

Table 2 provides a demographic profile of the home care aides who participated in this research. Four of the seven participants were between 55 and 64, one was between 65 and 74, one was between 16 and 24 and one was 25 to 34 years old. Five had a high school diploma or GED, one had some college, and one was a college graduate. All were women and all except
one was white. Race was not included in Table 2 to protect the participants’ identities. All had received nurse aide training directly from a home health agency where they were employed or were state certified nursing assistants. All resided in the rural area of southern Ohio where the study took place and most had resided there all of their lives. All home care aides cared for a PSP consumer whose PSP care manager completed the WMM Guide with them.

Table 2: Participant Descriptions

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Age</th>
<th>Education</th>
<th>Interview #</th>
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<tbody>
<tr>
<td>Mary</td>
<td>65-74</td>
<td>High school</td>
<td>1</td>
</tr>
<tr>
<td>Edna</td>
<td>55-64</td>
<td>High school</td>
<td>2</td>
</tr>
<tr>
<td>Starla</td>
<td>55-64</td>
<td>Some college</td>
<td>3</td>
</tr>
<tr>
<td>Pat</td>
<td>55-64</td>
<td>High school</td>
<td>4</td>
</tr>
<tr>
<td>Emma</td>
<td>16-24</td>
<td>High school</td>
<td>5</td>
</tr>
<tr>
<td>Lisa</td>
<td>55-64</td>
<td>GED</td>
<td>6</td>
</tr>
<tr>
<td>Tonya</td>
<td>25-34</td>
<td>College degree</td>
<td>7</td>
</tr>
</tbody>
</table>

Analysis

This analysis seeks to understand four broad issues: The impact of the WMM Guide on the relationship between the PSP consumer and their assigned home care aide, how the WMM Guide was implemented by the home care agency and if it had any impact on professional relationships, and to describe recommendations about the WMM Guide. While these issues relate directly to this study's research objectives, the home care aides were asked a few questions to not only help them feel more comfortable, but to also provide a bigger picture of how the WMM Guide might be impacted by the home care aides’ personal and professional experiences, daily job demands and their current knowledge of person-centered care. The following sections present the themes and topics that the home care aides addressed in their interviews.

Personal and Professional Experience

Every interview began with the home care aides being asked to describe how they came to work at the agency, how long they have been doing this work, and other places they have worked as an aide. Five of the home care aides have been doing this work between eleven and twenty-three years and three were state certified nursing assistants and had previous experience working in a nursing facility. The other four home care aides received training from the home care agency. Two of the home care aides were relatively new to this work. Several of the home
care aides described getting into this line of work after taking care of family members. They described themselves as “natural” caregivers. The home care aides who had prior work experience in a nursing facility reported that they enjoyed home health, because the work was not as physically demanding. They also reported that it was rewarding to provide “community support,” and that in home health the care was more “individualized” and they were encouraged to spend more time with the PSP consumers. Pat explained, “I like the home health better, I really enjoy that, you get to spend more time with them.”

**Daily Job Demands**

When asked how many different PSP consumers they see in a typical day, several of the home care aides expressed that they worked less than full-time, so other sources of income and benefits were not reduced, such as Social Security survivors benefit. The home care aides saw between two to four PSP consumers in a day. They described caring for these PSP consumers between six weeks to as long as twelve years. Edna reported that she sees four PSP consumers a day starting at 8:00 a.m. and has been with most of them for at least ten years. Most of the home care aides described filling in for other home care aides when they are off. Some of the PSP consumers were not seen every day, but some received as much as five hours of service six days a week. The home care aides described some needing assistance with bathing, but the majority needed assistance with meal preparation, cleaning, getting the mail and errands.

**Current Knowledge of Person-Centered Care**

The home care aides were asked what person-centered care or patient-centered care meant to them. One home care aide appeared to be familiar with the terminology of person-centered or patient-centered care, but all the other home care aides were unfamiliar with this terminology. They were asked if they could imagine what it means. Starla, who was familiar with the terminology, described person-centered care as, “The needs of the person making them the center of your care and doing what and taking them as an individual and how they would like to be treated, respect the individual.” Three of the home care aides thought the terminology was about the PSP consumer’s personal care service. Pat said she had never heard of the terminology before. She said she imagined it to mean, “I guess, I don't know how I want to word it, just making sure they get all of their personal care. They are what you are there for. That would be my center, taking care of them.” Edna, imagined person-centered care as, “It means helping
them get started for the day. Breakfast and then baths and then a little homemaking which consists of cleaning, dishes, sweeping, laundry, going to the store and then one-on-one time. They talk about their day and what they like to do.”

Providing Person-Centered Care

The home care aides were then asked how they provide person-centered care to their PSP consumers. Some of the home care aides described this being more than a job and that it is more about taking care of their PSP consumers. Mary said she provides person-centered care by doing, “Whatever they want done, one woman I fix her breakfast the way she wants, she always wants her hair fixed, so I'll wash and set it, clothes when she wants them. Different things, just whatever they want done.” Edna described her approach to person-centered care this way:

I go in and I wake them up. Some are up. Some of them let me in. We talk about the weather. I ask them if they are ready to start their day. I follow their lead, whatever they want to do. I will remind them to take their medicine. Many are up, but they wait for me to make their breakfast. All clients in their eighties and nineties. My first person is between eight and ten a.m., I start at eight every morning. Most clients are for two to three hours, depending on the shape they are in, so this gives me more one-on-one time.

Starla described her approach to person-centered care this way:

Listen to the consumer, ask them what they would like, giving them plenty of choices and trying to give them all the good choices and try not to highlight the bad choices. Open their eyes to see all the things available and avenues they can take. While still giving them the authority to say yes or no.

WMM Guide Implementation

All of the home care aides reported providing services to the PSP consumers prior to receiving the WMM Guides. While all of the home care aides had read their PSP consumer’s WMM Guide, only two reported reviewing it with the PSP consumer and putting a copy in their
home. This was the process suggested in the pilot study’s implementation manual. The other home care aides had received copies of the WMM Guide a few days to a week before being interviewed for this research. None of the home care aides reported receiving any formalized training on person-centered care or how to use the WMM Guide. They were asked to read the WMM Guides in preparation for their interview.

Impact of the WMM Guide on the PSP Consumer

When asked if they learned anything new or if they see any of their PSP consumers differently than before, most of the home care aides reported that they already knew them well by virtue of providing services to them for a while, by knowing them socially and in some cases, there was a kinship relationship. Several of the home care aides reported that when they first start with a new PSP consumer that they first sit and talk to them and ask them the kind of questions in the WMM Guide and share some information about themselves, so that sharing information is not just one-sided. Starla reported,

I read through the guide, but I already knew the client socially. Even though I knew her, on my first visit I sat down and talked to her about who I am. She knows me socially, but not as a caregiver. I try to tell her all the things I am there to help with and then I asked her what she needs. She said what she needed and it coincided with the guide. She made her needs very clear. I try to convey that I keep everything confidential.

Edna said,
Yes, I learned some new stuff out of there. Yes, I did see the client differently. When I read it and the different ways she likes things done, I understood it better. I went over the guide with her.

While reviewing the WMM Guide with a PSP consumer who has some cognitive deficits, Edna said the PSP consumer while laughing said, "who told them this?" Edna said “I told her either she did or her family.” Edna reported later,

I went over this with her and we discussed her bathing preferences, such as client liking
a sponge bath and hair brushed; it gave me insight into how to ease in there and get it done. In addition, that she did not like the larger vacuum used, because it was nosier. It let me know things I did not know.”

When asked if they were able to use any of the information in the WMM Guide to meet their consumer preferences, Edna reported the following:

I have used them all. We will start with who I am. I told her who I was and what I did and about her personal care, she is very private. It took a lot for her to let me give her a bath, because she did not want me to see her, so I told her we have the same thing, but mine is only fatter. She would laugh and then I could give her a bath. I told her that I treat her home just like I live here. She has certain ways she likes her stuff and that's what I do.”

Starla said the information was valuable. She said she did not see the PSP consumer as a “shopper,” which was reflected in the WMM Guide. She said, "Sometimes we think we know the people, but we really don't know the people."

Impact of the WMM Guide on the Home Care Aide

When asked if the WMM Guide gave them more control over their work, all of the home care aides expressed that the information in the WMM Guide would be helpful if they received it for new PSP consumers before they started services. Several of the home care aides reported being nervous when they first receive a new PSP consumer and when they first go into a home and that many of the PSP consumers will not tell them the information they need to know. As Starla stated, “It helps. This would have been very good if I did not know anything about her.” Lisa said, “It would save a lot of time; you could get right to work instead of investigating.” However, Tonya said, The WMM Guide still did not tell me what they expected such as if they want me to spend time talking to them or just come in and get the work done. Some want to talk your head off. Do they want more socialization? One I clean her house and she tries to help
and talks the whole time. What they expect would be helpful? What they expect us to do when we are in their house.

When asked what kind of things they think might happen as a result of receiving the *WMM Guide* information, Starla said, “You get to see them as a person. If they became a number or an object. If you just came in assumed this was how it was and did not listen to the client” To clarify, Starla was asked, “Having this guide helps you see them as person?” Starla clarified, No, I think if you just use this and if you are not careful like it tells all the needs and stuff, but if you do not listen to what they tell you. You can't take this as fact, you have to listen to them. You don't want to assume anything. Maybe today they just don't feel that way and you just start doing what this says and it may agitate them. You have to see them as a person and they have to have choices and respect. You catch someone who has had a hard day and this says they like to do their own dishes, but they may not want to do their own dishes, they had a had a hard day and have a headache. If you leave without doing their dishes then you left a part of your job undone. I say, you have to see that person as a person everyday. Guide can give you instinct into their case, but you can't go by guide alone. They are an individual with a life.

**Content, Structure and Process Recommendations**

Home care aides were then asked about some of the challenges and if they have any recommendations regarding the use or content of the *WMM Guide*. Starla said, “Would not change guide, but it would be better to get the guide before service starts. First day, you can go in and tell them about yourself and then use guide as a talking frame.” Tonya stated, “I don’t know, I like talking to my patients and they ask me about me, such as do I have kids. I like the way we do it, too. I'm nervous about going into a new home.” Most of the home care aides did not verbalize any challenges that were specific to the *WMM Guide*. When asked where the *WMM Guide* should be kept, the home care aides thought on the refrigerator, in the kitchen or in their room, on the home care aide’s clip board with other paperwork and some did not think it should
be kept in some PSP consumer’s homes. When asked what they would change about the *WMM Guide*, Edna said,

> Getting these a little earlier before I see the person, I learned she is not a morning person, so she is later noon to two. Would be good information to have in the beginning. When grocery shopping, they shop different from how you shop. I think having these first would help out a lot, I do.

She also thought that completing some sections of *WMM Guide* herself would be helpful. Starla wanted extra lines and an area for updates. Tonya said, “It depends on how the clients answer the questions. If they go in depth, such as about their bedtime routine, but if they just have a yes or no answer it is not as helpful. We need more details.”

In conclusion, the home care aides were asked if there is anything about the *WMM Guide* that they wanted to add. Several of the home care aides said that they think the information is useful if they receive it in a timelier manner, before services started. They also described currently relying more on verbal communication about a new consumer from their nurse supervisor or from the scheduler at the agency and relying less on the paper service activity plan that is developed by the nurse who opens the PSP consumer’s case before services start.

### Implications

*Value of WMM Guide Content and Structure*

All of the home care aides found value in the *WMM Guide*, especially if the information is received prior to their first visit with a new PSP consumer. Several of the home care aides described being anxious when first meeting a PSP consumer and how the *WMM Guide* would allow them to get to know them and their service preferences sooner. Several described that when they first go into a PSP consumer’s home that they could use the *WMM Guide* as a way to get to know the PSP consumers and their service preferences. Some saw value in completing pieces of the *WMM Guide* themselves. None of the home care aides thought the *WMM Guide’s* content or structure needed to be changed, other than adding a section for updates. Since many of the home care aides said they fill in for other aides when they are off work, they also saw value in having access to the *WMM Guide* for these PSP consumers. Additional training needs to be
completed with the staff members who will be completing the *WMM Guide* information to ensure the information is not only meaningful for the home care aides, but is also legible if this process continues to be paper-driven.

**WMM Guide Process**

The *WMM Guide* was developed to be a care management tool. Scripps Researchers knew that services would have already started at the provider level before the care managers completed the *WMM Guide* with their PSP consumers. The home care aides confirmed that the *WMM Guide* is going to have more value in their work and impact on the PSP consumer if the *WMM Guide* is completed at the assessment level prior to home care services starting. There was no agreement for where the *WMM Guide* should be kept. Some thought they should ask the PSP consumer where they want them to put the *WMM Guide* in their home and some due to concerns about confidentiality did not think it should be in the home. Using the paper form of the *WMM Guide* may be more challenging since many of the home care aides described more verbal communication with their supervisor and scheduler and less dependence on the nurse’s written service activity plan to know what they are supposed to do for their PSP consumers. In other geographic areas, home care aides may have less verbal communication and rely more heavily on the written service activity plan developed by the nurse.

**Person-Centered Care terminology**

A majority of the home care aides in this study had many years of experience taking care of others both professionally and in their personal lives. While they were not familiar with person-centered care terminology, they were all able to explain how they were able to provide what is considered person-centered care for their PSP consumers. They all expressed ways they show respect and provide choices to the PSP consumers they care for. The home care aides also had developed relationships with many of the PSP consumers they cared for. This made the information in the *WMM Guide* less valuable since they were not learning new information on the PSP consumers they help. The level of caring experience and the richness of the relationships in this part of Ohio may be unique. The *WMM Guide* introduces a more formal structure for this to occur and may be less valuable in some geographic areas.
Provider Buy-in

With the exception of one agency, there appeared to be a lack of buy-in for use of the WMM Guide. Reasons for this may include not receiving or reviewing the project’s implementation manual, receiving too few WMM Guides, concerns about violating the Health Insurance Portability and Accountability Act (HIPAA), duplication of things they already do, and finally not having the time to implement the WMM Guide. If incorporating more formalized structures for person-centered care within the PSP program is going to be successful, providers are going to need to see the value of the WMM Guide or other tools at the management level.

Provider Oversight, Training and Resources

Providers are going to need additional training on person-centered care and how to use any new tools, such as the WMM Guide to ensure that every PSP consumer is receiving person-centered care across the state of Ohio. PAAs are going to have to lead the way and provide direction to their contracted PSP agencies. In order to give PAAs oversight and control, ODA and PAAs may need to consider revising PSP service specifications to include person-centered care language and training requirements for provider staff. Service specifications can also be written to give more flexibility for the care managers and provider staff to help PSP consumers work towards their personal goals. Finally, HIPAA considerations will need to be part of the training. Several of the home health aides and other staff at the provider agencies were concerned about violating HIPAA by sharing the WMM Guide information.

Limitations

Before this study began, its success was dependent on several factors. First, we were depending on the PSP care managers and PSP consumers working together to complete the WMM Guide that contained meaningful and legible information from the PSP consumer’s perspective of what matters most to them and their service preferences. Second, we were dependent on the home health staff, including the scheduler, nurse supervisor and home health aide reading and implementing the pilot study’s implementation packet that the Scripps research staff developed. Third, we were dependent on the home care aides being agreeable to be interviewed. Finally, we did not know how the WMM Guides would be distributed over the five county areas.
During focus groups held in December, 2014 with AAA7 staff and home health agency staff, most of the participants reported not receiving the WMM pilot study’s implementation manual that was developed by Scripps research staff. These were e-mailed and put in the Miami WMM project site’s resource folder. After the meeting in December, they were sent out again to all study participants. It was decided prior to the end of the pilot study to let the implementation process between the AAA7 staff and provider staff to flow without intrusion from the Scripps research staff.

At the end of the pilot study, follow-up with provider staff found that with the exception of one home care agency, they did not implement the final steps for the pilot study. This affected the sample available for this part of the pilot study. Many of the gatekeepers at the home health agencies could not be reached by phone or e-mail. When contacted, some reported that they did not do anything with the WMM Guides and some reported being too busy to arrange interviews with the home health aides. Another issue that arose was the large rural area that some of the agencies served. The gatekeepers at the agencies did not want to ask their home health aides to drive too far for the interview, so we were limited to the home care aides who lived near the office. All of these outcomes limited the sample available to be interviewed. Despite these limitations related to the early implementation stage the overall project was in, interviews with the home care aides provided valuable insights about their role in person-centered care, and about how best the WMM process might be structured.

**Conclusions**

This study explored four main areas of inquiry as pertaining to the *WMM Guide*: (1) to understand if the *WMM Guide* had any impact on the relationship between the PSP consumer and their assigned home care aide; (2) how the *WMM Guide* was implemented by the home care agency; (3) if it had any impact on professional relationships at the agency level; (4) obtain recommendations about the *WMM Guide*. The seven home care aides all saw value in the *WMM Guide* if it is received prior to seeing a new PSP consumer for the first time. Several of the home care aides did learn something new about their PSP consumers and were able to use the information to meet their preferences. However, the *WMM Guide* did not have the opportunity to help the home care aide get to know the PSP consumer and their service preferences since they had already developed relationships. The *WMM Guides* were not utilized as well as they could
have been according to the pilot project’s implementation manual so its impact on professional relationships at the agency could not be evaluated. There was a lack of buy-in at the provider level and this will need to be addressed either through training, demonstrating the benefits of person-centered care, policy change, building this requirement into contracts, and if needed, financial penalties.

In summary, this study demonstrates that implementing person-centered care practices will have its benefits and challenges. It is important to keep in mind that the PSP program cares for a vulnerable population and many of the home care aides caring for them are at risk for hardships. While the attempt to provide person-centered care is a noble cause, policy makers have to be careful to ensure that this process remains focused on people and not on paper. While the WMM Guide provides a formal structure to obtain and document a consumer’s needs, strengths, goals and service preferences, coming up with the next steps will be more complicated since the home and community based Medicaid waiver program is so fragmented and service options are also limited by current Ohio rules and regulations.

**Future Studies**

This is the first of many studies that will be needed for the field to implement person-centered care if it is going to meet the new federal guidelines to receive federal funding for their home and community-based Medicaid services. In future studies, the WMM Guide will need to include more suburban and urban areas since their workforce may be significantly different from this sample. Future studies also need to include more oversight of implementation of the WMM Guide at the home care provider level. In order to provide this greater hands-on assistance a smaller number of home care providers may need to be selected.

This study started to glean some best practices that seasoned home care aides follow, such as initial ways to develop a good working relationship and giving options every time services are provided. Future studies could more formally examine person-centered care best practices from the perspective of home care aides and PSP consumers. Another area of focus for future studies is how to integrate the home care aide into agency communications. Is there a better way for the PSP care team, including the PSP care manager, nurse supervisor and home care aide to work with PSP consumers and their families to ensure their care needs and preferences are being met? Can the PSP care team work with PSP consumers and their informal
supports to develop and work towards meeting specific goals? What would that look like?

Finally, while the *WMM Guide* is a good tool, a future study could investigate the best methods to share this information with home care aides and if it can be integrated into the current service activity planning process.
Appendix A

What Matters Most Guide Framework and Questions

What Matters Most: A Guide for My Support and Care

II. MY SOCIAL SUPPORTS
Who my natural supports are
Who I want to be involved in my care and support

Ia. Who I am
What makes me who I am
How I like to spend my day, and with whom

Ib. My goals
What I seek for my daily life and the future

III. MY PERSONAL CARE
How I like my health and hygiene to be cared for
What I can do

IV. MY HOUSEHOLD CARE
How I like my home to be cared for
What I can do

What I hope will happen as a result of my support/care plan

Developed by Scripps Gerontology Center, Miami University
What Matters Most: Detailed Preference Interview Questions

**I (a): Who I am**

“To start with, I am going to ask you some questions about yourself so that I can get to know you a little better.”

1. In a sentence or two, how would you describe yourself? In other words, what makes you who you are? *(If clarification is asked, use some examples: good listener, spiritual person, likes to be alone or likes to be with people, animal lover, a veteran)*

2. Walk me through a typical day for you. *(If clarification is asked, use some examples: what did you do yesterday, what are you going to do tomorrow, who do you typically spend time with)*

3. What makes it a really good day for you? *(If clarification is asked, use some examples: hobbies, going for a drive, getting outside, talk/visit with family/friends)*

4. Are there things you used to enjoy that you think you can no longer do, but might be able to do with help? *(If clarification is asked, use some examples: reading, cooking, going to church, getting out)*

5. What are your biggest concerns and worries right now?

6. Is there anything that is important for your helpers to know about your spiritual or religious beliefs?

6a. What about your cultural background or cultural practices?

**I (b): My goals**

“Now we’re going to talk a bit about your goals for your future.”

7. In a sentence or two, what are your dreams and goals for the future? *(If clarification is asked, use some examples: things you want to do, people you want to see, goals for your health)*

8. What do you hope will happen as a result of being in the PASSPORT program?

**II: My Social Supports**

“Now that I have gotten to know more about you, I would like to ask you more about your social supports.”

9. What family members/friends/neighbors do you enjoy regular contact with and what is your relationship to them?

10. Are there family members/friends/neighbors with whom you prefer NOT to have contact?

11. Are you, or have you been, involved with any community groups or clubs? Which ones?

11a. Religious organizations? Which ones?

12. Are you able to stay involved enough with family members and friends?

☐ Yes  ☐ No

12a. Is there anything you need that could help you stay better involved with them? *(If clarification is asked, use some examples: transportation, communication devices such as a special phone)*

**III. My Personal Care**

Do you receive help with personal care, like bathing or grooming?

☐ Yes  ☐ No

Notes:___________________________________________________________

__________
“Now I am going to ask you about your personal care preferences.”

13. What time do you usually like to get up in the morning? ___________________________________

13a. How important is it to you to get up at that time?

☐ Very  ☐ Somewhat  ☐ Not very  ☐ Not at all

14. Walk me through your usual morning routine.
14a. How important is it for you to follow your morning routine?

☐ Very  ☐ Somewhat  ☐ Not very  ☐ Not at all

14b. What could make your morning routine go better?

15. What type of bathing do you prefer? (Mark all applicable)

☐ Tub bath  ☐ Sponge bath  ☐ Shower  ☐ Bed bath  ☐ Standing  ☐ Sitting

☐ Other/Notes: ______________________________________________________________

15a. How important is this to you?

☐ Very  ☐ Somewhat  ☐ Not very  ☐ Not at all

16. How often do you like to bathe?

☐ Daily  ☐ Every other day  ☐ Once a week  ☐ Twice a week  ☐ Three times a week  ☐ Other:

☐ Other:

Notes: ______________________________________________________________

16a. How important is it to you that you bathe that often?

☐ Very  ☐ Somewhat  ☐ Not very  ☐ Not at all

17. Are there any day(s) and/or times of day when you would not want someone to help you bathe? (If clarification is asked, use: For example, some people might have visitors on Wednesdays, so Wednesdays would not be good; other people might have religious obligations that might interfere with having someone in their home)

☐ Yes (please mark days)  ☐ No (SKIP to 18)

☐ Monday  ☐ Tuesday  ☐ Wednesday  ☐ Thursday  ☐ Friday

17a. How important is it that your bathing is done on a particular day or time?

☐ Very  ☐ Somewhat  ☐ Not very  ☐ Not at all

18. Is there anything your helper needs to know about any special needs you have when using the bathroom?

☐ Yes  ☐ No

19. Are there things that are important for your helper to know about your hair care or grooming? (If clarification is asked, use some examples: wash, comb, brush hair, shaving)

19a. Are there things that are important for your helper to know about your mouth care? (If clarification is asked, use some examples: brush teeth, clean/soak dentures)
20. When it comes to what you wear on a typical day, are there things that are important for your helper to know? *(If clarification is asked, use some examples: wear a bra every day, compression stockings)*

21. Do you like to nap? □ Yes □ No (SKIP TO 22)

21a. When do you like to nap?

□ Morning □ Afternoon □ Evening/night □ Whenever I feel sleepy

Notes: ________________________________________________________

22. What time do you usually like to go to bed? ____________________________________

Notes: ________________________________________________________

22a. How important is it to you to go to bed at that time?

□ Very □ Somewhat □ Not very □ Not at all

23. Do you have a particular bedtime routine? □ Yes □ No (SKIP TO 24)

23a. If yes, walk me through your bedtime routine.

23b. How important is it for you to follow your bedtime routine?

□ Very □ Somewhat □ Not very □ Not at all

23c. What could make your bedtime routine go better?

24. When it comes to your meals, do you have any concerns about how your meals are prepared?

*(If clarification is asked, use these examples: cutting food, seasoning, allergies, and religious/cultural restrictions)*

24a. Are there parts of preparing meals that you prefer to do yourself? What do you like to do?

*(If clarification is asked, use these examples: washing/peeling vegetables, setting table/utensils)*

24b. When it comes to your grocery shopping do you have any special instructions?

□ Yes □ No

Ask only of Consumers who need help with eating:

24c. Are there things that your helper should know about helping you eat?

□ Yes □ No (SKIP to 25)

IV: My Household Care

Do you receive help with cleaning or housework? □ Yes □ No

Notes:________________________________________________________

“Now I would like to ask you a bit about your preferences regarding services involving your home.”

25. Are there things that are important for your helper to know about how you want your cleaning done? *(If clarification is asked, use these examples: using bleach or certain products, instructions to clean bathroom or kitchen, dusting, vacuuming)*

25a. Are there parts of housework that you prefer to do yourself? What do you like to do? *(If clarification is asked, use these examples: drying dishes, dusting)*

26. Do you have a particular day or time when you prefer your cleaning to be done?
26a. Are there any day(s) and/or times of day when you would not want someone in your home helping you? *(If clarification is asked, use: For example, some people might have visitors on Wednesdays, so Wednesdays would not be good; other people might have religious obligations that might interfere with having someone in their home)*

☐ Yes (please mark days)    ☐ No (SKIP to 27)

☐ Monday    ☐ Tuesday    ☐ Wednesday    ☐ Thursday    ☐ Friday

26b. How important is that your cleaning is done on a particular day or time?

☐ Very    ☐ Somewhat    ☐ Not very    ☐ Not at all

27. Are there any specific instructions for caring for your laundry? *(If clarification is asked, use these examples: gather and sort, use washing machines/dryers, hang/fold/put away clothing)*

☐ Yes    ☐ No

27a. Are there parts of laundering that you prefer to do yourself? What do you prefer to do? *(If clarification is asked, use these examples: sorting or folding laundry, washing delicate items)*

28. With regard to having someone come into your home, what are the most important concerns you have about your safety?

29. Thinking about the person who helps you with personal care and homemaking, are there skills or knowledge that are especially important for them to have?

30. Is there anything about your needs or preferences that we have not talked about that you would like me and those providing your care to know?

31. In summary, of all the things we have talked about, what matters most to you? *(Review some of the general areas.)*

32. Where would you like this information to be placed as a quick reference so everyone involved with your care will know What Matters Most to you?

   “Thank you very much for taking this time with me. We will all do our best to use what you have told us to arrange the right services, at the right times, and in the right way, according to your preferences. We will be checking with you to see how well your preferences were met.”
Appendix B

*What Matters Most Guide* pilot study process

- Reasonable Consumer expectations & preferences are met.
- Improved outcomes.

- Designated Point Person
- Scheduler
- Nurse Supervisor

- Consumer
- PP Service Plan
- Home Care Provider
- Adjusted PP Service Plan
- Adjusted Provider Care Plan
- Aide

- WMM Guide
- Consumer
- Assessor
- Care Manager
- WMM Guide
- WMM Guide
Appendix C
Recruitment letter

Date
Owner/CEO
Agency name
Street
City, OH zip code

Dear Owner/CEO:

We want to thank you and your staff for your involvement in assisting Scripps Gerontology Center (Miami University) in partnership with AAA7’s recent pilot testing of the What Matters Most: A Guide for My Support and Care. Scripps is now seeking input about the design of the guide, about the strategies for communicating the information gathered, and about its value to you as a provider. As part of this process, we are planning on documenting the experiences of the home care aides in using the What Matters Most: A Guide for My Support and Care. Of particular interest is how it impacted their work and relationships with their nurse supervisors and consumers.

As part of this pilot project your agency received several of the What Matters Most guides for your staff to use with your PASSPORT consumers. I would like to interview at least four of the home care aides who used the What Matters Most guide with the PASSPORT consumers they help from your agency. These interviews will be for one hour and I am hoping to use a private conference room at your agency. I can try to find another location in your area if this is not feasible. Home care aides will receive $20.00 cash as compensation for their time.

All of us have a real opportunity to have an impact on what this guide looks like and how it gets used before it is implemented across the state. I am asking you to please follow up with your home care aides who were a part of this pilot and advise me if they are interested in being a key informant for our study. I will follow up with you in the next week to see if there was any interest and how I can help make these interviews happen.

If you have any questions about this part of the pilot project evaluation, please call Heather Nelson at ###-###-#### or e-mail at, name@miamioh.edu. I look forward to speaking with you soon.

Thank you for your time and participation in this very important project.
Sincerely,

Heather Nelson, LSW
Scripps Gerontology Center
Appendix D

Participant Consent Form

What Matters Most: PASSPORT Home care aides’ views on Ohio’s initial steps to implement person-centered practice

KEY INFORMANT
CONSENT TO PARTICIPATE
Scripps Gerontology Center
Miami University
Oxford, OH 45056

I understand that I am participating in an interview as part of a project about PASSPORT consumer preferences related to home care services. The project is being conducted by the Scripps Gerontology Center at Miami University, in partnership with Area Agency on Aging District 7, Inc. (AAA7), and is funded by the Ohio Department of Aging (ODA). The goals of the study are to document the experiences of the home care aides in using the What Matters Most Guide. My input and the input of PASSPORT care managers, consumers, providers and other stakeholders will help the Ohio Department on Aging and Scripps Gerontology Center to determine how to best modify and implement the What Matters Most guide and related processes with PASSPORT consumers.

I am being asked to participate in one interview that will take approximately one hour. I understand that I will be compensated $20.00 for my time. I understand that it will be my responsibility to report this income on my tax return.

I am at least 18 years of age and understand that participation in this interview is completely voluntary, and that I may decline to participate, decline to answer specific questions, or withdraw from the study at any time, with no negative effect on my employment.

I understand that this key informant interview will be audio-recorded for research purposes; the recording will be transcribed and then erased. The transcript will include my initials only. My identity will be known only to the student principal investigator. The three researchers assisting the student principal investigator will have access to the transcripts and field notes. The student principal investigator will store my name and contact information in a locked file until January 1, 2016.

Results from this study may be used in publications or presentations. No reports, presentations, or publications will include my name or any information that might identify me or my comments.

I am freely giving my consent to participate. I may contact Miami’s Office for the Advancement of Research and Scholarship, (513) 529-3600 or humansubjects@miamioh.edu if I have any questions about my rights as a participant in this project.

I can contact Dr. Suzanne Kunkel at the Scripps Gerontology Center, (###) ###-#### or name@miamioh.edu if I have any questions about this project.

Name:________________________________________________

Date:________________________________________________
Appendix E

Interview Guide

Participant’s Initials: _________  Gender: M/F
Date:__________________________  Time started: ________  Time finished: ________

**WWM Interview guide**

**Introduction/consent process**
Thank you for agreeing to participate in this interview with me. I have been working on the What Matters Most project for nearly a year and as part of my studies, I wanted to interview the home care aides who worked directly with the PSP consumers who completed the WMM guide with their PSP care managers. My interviews are part of a research project, so I need to obtain your written consent to participate. I want to let you know that your participation is voluntary, your responses will be kept confidential, they will not be shared with your employer, and you can withdraw at any time without negative consequences.

I will give you some time to read the consent form. When you are ready, you will receive a copy to take with you and I will keep a signed copy for my records.

Thank you, I will now turn on my tape recorder, so we can get started with the formal interview. I will also be taking notes as you talk.

**Interview**

“Now I am going to go question by question. Remember, there are no right or wrong answers. Your opinion is extremely important so please feel free to say whatever you are thinking.”

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<tr>
<th>Questions</th>
<th>Notes</th>
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<tr>
<td>1. To get started, tell me the story of how you came to work at this agency. I’d like to hear about <strong>how long</strong> you’ve been doing this work, other <strong>places</strong> you’ve worked as an aide, and a little about your job here.</td>
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<td>2. How many different PSP consumers do you see in a typical <strong>day</strong> and <strong>week</strong>? How <strong>long</strong> have you been with these same consumers?</td>
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<td>Questions</td>
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<td>3: What does “person-centered care” mean to you?</td>
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<td>4. How do you provide person-centered care to your consumers?</td>
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<td>Interviewer will pull out a blank copy of WMM guide to use as a reference.</td>
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<td>5. Tell me how you got started with the WMM guide. The <strong>training</strong> you received, things your <strong>supervisor</strong> did to get you started, and about the <strong>communication</strong> and <strong>support</strong>, you received from your supervisor and other agency staff?</td>
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<td>6. Have you used the WMM guide to meet consumer preferences? Which ones? Were there any you weren’t able to meet? Why not? If you haven’t used it – why not?</td>
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<td>7. Did you learn anything new, or <strong>see any of your consumers differently</strong> than before? If you haven’t used it – why not?</td>
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<td>8. Where do you think the information in the guide should live? How is it best to communicate the consumer’s preference information to you?</td>
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<td>9. Did this process give you more or less control over your work (empower)?</td>
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Or Do you think this process would give you more or less control over your work?

10. What kinds of things might happen because of using the WMM guide with consumers?

11. What are some of the challenges to using the WMM guide?

12. If you could change anything about the WMM guide, what would you change?

“Thank you, now I need to ask you some basic questions about yourself, so I have a general description of the people I am talking to about the guide. “

Please check one of the following:

13. What is your age?

- [ ] 16-24 years old
- [ ] 25-34 years old
- [ ] 35-44 years old
- [ ] 45-54 years old
- [ ] 55-64 years old
- [ ] 65-74 years old
- [ ] 75 years or older

14. Please specify your ethnicity or race:

- [ ] White
- [ ] Hispanic or Latino
- [ ] Black or African American
- [ ] Native American or American Indian
- [ ] Asian / Pacific Islander
- [ ] Other ________________________________
15. What is the highest level of formal education you have completed?

- [ ] Less than high school
- [ ] High school
- [ ] GED
- [ ] Some college
- [ ] College degree
- [ ] Advanced degree

16. I want to thank you for your time today, is there anything about the WMM guide that I haven’t asked you and it is important for me to know?

“Again, thank you for your time. I did obtain approval to provide you with some compensation for your time today. Here is $20.00. However, I will need you to complete the bottom of this form and you may keep the extra form for your records. This information is for Miami’s internal auditing purposes only and will be kept confidential.”
References


Donica, K. (2012). Overview of the Balancing Incentive Payment (BIP) Program
Retrieved from:
http://ohioaging.org/PDFs/7.%20The%20Balance%20Incentive%20Program%20-%20Kim%20Donica.pdf


