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EXAMINING STATE EFFORTS IN REBALANCING LONG- TERM SERVICE AND
SUPPORTS FROM INSTITUTIONAL TO HOME AND COMMUNITY BASED SERVICES

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ABSTRACT

Background: The United States population is aging, putting an increased demand on long-term service and supports (LTSS). Furthermore, an increasing number of elders requiring LTSS will seek services in the comfort of their home for as long as possible, rather than moving into an institutional setting. The purpose of this study is to observe and analyze three areas of rebalancing long-term care for three states with the hopes of determining commonalities in funding projections, barriers to rebalancing, and more. **Methods:** This study utilizes case studies and interviews to gather data. Preliminary screening was done with the AARP 2014 State Scorecard Summary of LTSS System Performance Across Dimension. The scorecard measures all 50 states and the District of Columbia in five areas of LTSS performance, giving them rankings per category and an overall category compared to the other states. Three states were chosen based on their rankings. Oregon was selected as the high performing state, ranking 3rd; New Jersey for the middle performing state, ranking 26th; and Kentucky for the bottom performing state, ranking 51st. Next, three people per state were selected for interviewing. The contacts included each state's AARP director, the Medicare director, and the secretary on aging. Each contact would be asked the same set of questions specific to their state, providing unique answers around the same themes. **Results:** All three states believe home and community based services are the future of long-term care and what aging citizens in their states prefer. However, Kentucky is the only state that funds more institutional based care. Funding is a large element impacting a state's ability to commit to rebalancing long-term service and supports. Oregon described the most programs to provide money for home and community based services and also

was cohesive in coordinating future projects. New Jersey is at the forefront for state funded programs for caregiver's emotional needs.

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Chapter 1

Background

In the United States long-term service supports (LTSS) have been traditionally delivered through institutional based settings. However, recently, states have been shifting care to home and community-based services (HCBS). The Affordable Care Act (ACA) of 2010 incentivizes states to improve their LTSS through rebalancing care from institutional to home and community based services. In 2015, the ACA called for the creation of a 15-member commission of long-term care, with the purpose of coming up with a plan to implement a system to provide LTSS to elderly and disabled Americans in need (National Health Policy Forum, 2013). LTSS are meant to assist in activities of daily living and instrumental activities of daily living. Some examples of LTSS services include: walking, grooming, bathing, and dressing, which are activities of daily living and additionally: shopping, cooking, driving, housework, and medication management, which are instrumental activities of daily living (Weston, 2014). In 2013, there were an estimated 12 million Americans in need of LTSS; however, with the elderly population increasing the estimated usage of LTSS by 2050 will jump to 27 million Americans (National Health Policy Forum, 2013). This jump presents a need for creativity and expansion of providing LTSS. The need to expand HCBS is further demonstrated by research from these future LTSS users preferring to age in their home, rather than in an institution. Overall, states must understand in the next 30 to 40 years the elderly population will increase drastically, and the majority of the LTSS users will seek such services within their home (Musumeci & Reaves).

Through preliminary research of a small literature review, three general themes for states rebalancing long-term care from institutional to home and community based settings were highlighted. The initial search produced 20 articles in which three were applicable for review; many excluded for a lack of empirical results. Then, three central themes, listed below, allowed for me to find related articles from PubMed and Google Scholar to create a foundation for a literature review and theme discovery with eight articles. The first theme utilized for the study is the cost effectiveness of rebalancing care (Mitchell et al., 2006; Kaye et al., 2009; Chattopadhyay et al., 2013). The second is related to transitioning residents currently in institutions to home and community based settings (Holup et al., 2015; Robinson et al. 2015; Bardo et al. 2014). The final theme is the emotional significance LTSS users attach to aging in place rather than in an institution (Wiles et al., 2011; Tang & Lee, 2011). The purpose of this study is to utilize the three developed themes to explore three different states ranked as high, medium, and low performers of rebalancing LTSS delivery from institutional to home and community based settings and examine issues and benefits of providing home and community based services.

The study addresses LTSS programs such as the Balancing Incentive Program (BIP), the All-inclusive Care for the Elderly (PACE) program, and the Money Follows the Person Demonstration. The BIP incentivizes states to increase HCBS through grants to create or expand new non-institutional services. Medicaid explains the BIP, “increased the Federal Matching Assistance Percentage (FMAP) to States that made structural reforms to increase nursing home diversions and access to non-institutional LTSS” (Medicaid, 2017b, para. 3). The program has allowed states to create “no wrong door systems” where people can log onto Medicaid's website and have a simple way of finding information for LTSS. Additionally, BIP allows for the

implementation of conflict-free case management for participants. The PACE program is another Medicaid program, which provides medical and other services to dual eligible elderly citizens. PACE funding is capped, meaning the provider does not have to worry about what services will be reimbursed and can instead provide any services necessary for the individual. In order to be eligible for PACE, a person must be 55 years or older, be able to live in their community safely, and also be nursing home eligible (Medicaid, 2017a). The money follows the person program is a Medicaid program which hopes to move elderly citizens from institutions, such as nursing homes, back into the community. These elders either move into their own home or a loved one's home. The program grants states with money to develop their own money follows the person program (American Elder Care Research Organization, 2016). Each state is responsible for setting up their own program if they wish to participate, as of 2014 there are 44 states that with active or developing programs (American Elder Care Research Organization, 2016).

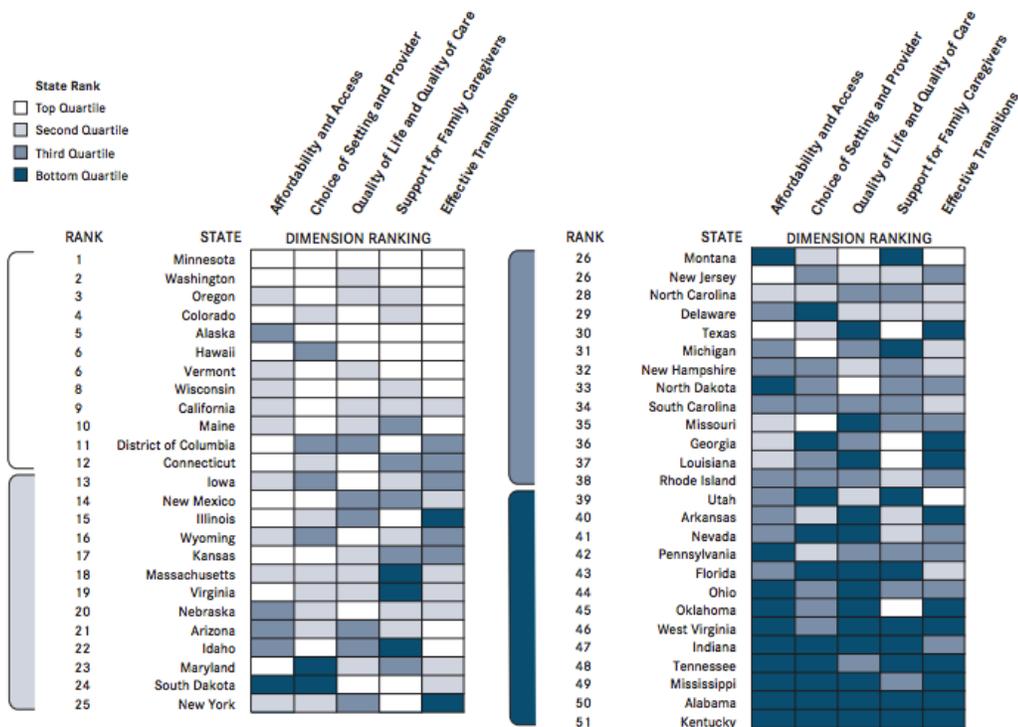
Chapter 2

Methods

The goal of the study was to utilize case studies with nine interviews total, three for each state. I chose three states for interviewing based on the AARP, “State Scorecard Summary of LTSS System Performance Across Dimension” (AARPb, 2014, p. 1). The scorecard measures all 50 states along with the District of Columbia in five areas of LTSS performance, “affordability and access, choice of setting and provider, quality of life and quality of care, support for family caregivers, and effective transitions” (AARPa, 2014, p. 1). Three states were selected based on their overall rankings. For the high performing state Oregon, ranking 3rd overall was selected. For the middle performing state New Jersey, ranking 26th overall was selected. Finally, for the lowest performing state Kentucky was selected, ranking 51st overall (AARPb, 2014). The chart of each state’s ranking is shown below in Figure 1.

Figure 1 State Selection

State Scorecard Summary of LTSS System Performance Across Dimensions



Note: Rankings are not entirely comparable to the 2011 Scorecard rankings in Exhibit A2. Changes in rank may not reflect changes in performance, and should not be interpreted as such.
 Source: State Long-Term Services and Supports Scorecard, 2014.

* AARP, The Commonwealth Fund, & The Scan Foundation. (2014).

The study utilizes key informant interviews for the overall qualitative case study collecting information to be compared with hopes of highlighting similarities and differences in rebalancing efforts between the states. Table 1 depicts the contacts for each state and the agency and department they work for within their state. Furthermore, the study sought to understand possible barriers to rebalancing care. By utilizing multiple smaller case studies, the study is able to focus specifically on each state without overgeneralizing, and further allows for comparative analysis for conclusions to be drawn. Upon completion of the interviews and distinctive case studies the interview responses are analyzed and compared both within state and between the different states. The study design allows for the exploration of multiple people and agencies

involved in rebalancing care so more significant details could be retrieved from unique perspectives.

Furthermore, three contacts for each state were selected for the interviews, each interview would last 20-30 minutes and each contact answered the same set of questions, revolving around the three identified themes mentioned above (interview questions found in appendix A). For the study I would speak the state Medicaid director, the state secretary on aging, and the state's AARP chapter director. The Medicaid director was selected because they are directly involved with the incentives for rebalancing long-term care. Furthermore, the secretary on aging was selected because they would hopefully be very familiar with the state's elderly population and the needs that have been met for their elderly population and the gaps that still exist when it comes to rebalancing care. Finally, the AARP director was selected because it is a non-profit organization designed to help retired Americans. AARP offers many benefits to members and could provide unique information for the study because of its role as a major legislative advocate for elderly in both federal and state arenas. Each contact would have unique answers and perspectives to the interview questions all focusing around the state's individual position in rebalancing care.

The interview questions are semi-structured, allowing for reliability because all the informants would be asked the same questions; however, each informant can take the question in a unique direction answering it utilizing information specific to their job title and background information. Along with the interview questions, multiple interviewees provided supplemental research materials that provide fuller details to the state case studies.

Additionally, there is a study limitation; I was unable to interview the AARP contact for New Jersey. After reaching out multiple times I received no follow up. This limitation was balanced

by researching AARP New Jersey through pamphlets and online resources. A second possible limitation is that Nancy Day spoke on behalf of both the aging department within the Department of Human services and New Jersey Medicaid because they are sister state agencies within the same department and she felt knowledgeable to answer the questions for both sides. Day additionally provided multiple online resources for both the department of aging and Medicaid for supplemental information. The two elements resulted in less firsthand information from New Jersey, however supplemental information filled in gaps and Nancy Day was knowledgeable on both Medicaid and DHS information for the state.

Table 1 Contact List

First Name	Last Name	State	Department	Phone Number
Mike	McCormick	Oregon	DHS	503-945-6229
Dana	Hittle	Oregon	CMS	503-945-6491
Jon	Bartholomew	Oregon	AARP	503-513-7370
Nancy	Day	New Jersey	DHS (CMS)	609-588-6562
Tonia	Wells	Kentucky	DAIL	502-330-6861
Lori	Gresham	Kentucky	CMS	Lori.gresham@ky.gov (Gresham called me)
Eric	Evans	Kentucky	AARP	502-394-3427

Chapter 3

Oregon

Background

Oregon was selected as the top performing state for rebalancing LTSS based on its AARP scorecard ranking of third overall. Oregon's Department of Human Services posts, "Oregon has led the nation in providing long-term services and supports to people in their homes and communities" (Oregon DHS, p. 1, 2017). Oregon's scorecard highlights the state ranked first in "effective transitions" and fifth in "choice of setting & provider", furthermore, Oregon did not fall below 20th for any of the other categories for the AARP scorecard (AARP, 2014). Jon Bartholomew, the director of government relations for AARP Oregon was interviewed first. Mike McCormick the Aging and People with Disabilities Deputy Director for the department of human services for Oregon was interviewed second. Finally, Dana Hittle, in the office of health policy of Oregon was interviewed.

Cost Effectiveness

When asked about cost effectiveness regarding the percentage of money spend on home and community based services versus institutional based services, Bartholomew, of AARP answered without a specific number but felt the state advocates and puts more resources towards

HCBS, stating, “Oregon has 85% of the nursing home eligible in home and community based care settings” (Bartholomew, Interview, 2016). McCormick of DHS provided a financial breakdown, “the budget for two years is \$2,664,359,642 for home and community based and institutional care combined. The Institutional portion is \$823,339,296” (McCormick, 2016). So through calculation the portion of the budget for institutional based care is only 30.9%, which is a minority of the overall long-term care budget. The monetary breakdown supports Oregon’s avocation for HCBS over institutional care. Hittle explained the DHS budget is the same as the CMS budget because they are “sister agencies, and the state Medicaid agency works collaboratively with DHS” (Hittle, 2016).

Next, when asked about advocating in general towards HCBS or institutional Bartholomew had a passionate response. He replied, “many years ago we put into the state statute principles that we use as a mantra (agency, legislative, advocates, etc.) our system is based on principles: independence, choice, and dignity. The state agencies advocate for keeping people in their homes not just through Medicaid” (Bartholomew, Interview, 2016). McCormick agreed, the trend lines will continue to shift towards funding home and community based services adding the overall expenditures for long-term care are increasing especially with the shift in demographics being so prominent there will be more money put towards the elderly and HCBS. Hittle agreed with the future trend lines shifting towards HCBS, agreeing again that Oregon advocates more for community-based care. Hittle replied, “there are several initiatives to help diminish institutional based care” (Hittle, 2016). Further explaining, Oregon is attempting to get citizens out of institutions wherever possible. Bartholomew later describes the, “The Oregon Project Independence” which is for people who are not Medicaid eligible but could become so in

the future and seeks to keep this population safely in their home and off of Medicaid (Bartholomew, 2016).

The final financial question regarded funding and whether or not Oregon expected shifts in the future. Bartholomew highlighted how funding envelopes many factors. He mentioned funding for HCBS is going up due to caseload increase and the cost per case is increasing. Oregon saw a recent increase in HCBS funding Mr. Bartholomew attributed the increase to the ACA allowing more people onto Medicaid and an increase in younger people with disabilities eligible for LTSS. Oregon saw, “about 20% increase in estimated cost [for HCBS] that we expect to level out” (Bartholomew, 2016). A big factor to funding, Bartholomew highlighted, is the department of labor ruling on Fair Labor Standards Act (FLSA). With the ruling, the state is now a co-employer for the home care provider. Bartholomew explained before the ruling the LTSS user, or their family would act as the employer for their provider, but the state would deal with paperwork, payroll, and benefits. However, the new ruling on the FLSA could potentially add costs for HCBS, as the state may be required to pay increased wages for personal care attendants and home aides.

Transitioning

Next, the interview asked about transitioning individuals from institutional to HCBS. When asked about the “Money Follows the Person” demonstration, Bartholomew mentioned Oregon did not have the best history with the program, “it was originally introduced to the people working at DHS, the rules weren’t followed and it unfortunately led to people being fired and left and overall ‘bad taste’ which dramatically reduced the program usage” (Bartholomew,

2016). McCormick agreed to what Bartholomew stated regarding the Money Follows the Person demonstration. He explained the reason for backing out of the program as, “the combination of over burdensome regulatory requirements as well as lower opportunity to take advantage of the program” (McCormick, 2017). Further stating Oregon was already very well balanced and did not have as many opportunities to take people out of institutions and place them in their home. Hittle relayed McCormick would have more knowledge on the Money follows the person demonstration and the Medicaid department did not have a unique roll with Oregon’s decisions to pull back from it (Hittle, 2016).

Bartholomew, when asked about the “All Inclusive Care for the Elderly--PACE” program mentioned it is starting to expand in Oregon; he credited this program with helping keep the adult day care centers operating. Bartholomew explained Oregon does not have a lot of options for family caregivers, explaining there are less than 20 adult day care centers that accept Medicaid beneficiaries, so some of them partner with PACE to help stay open (Bartholomew, 2016). McCormick has positive feelings towards the PACE program as well, mentioning the program is expanding at a steady rate over the years. McCormick highlighted the “Metro” region in Oregon represents a region where the program is growing and expanding. However, “Providence” Oregon has only one contractor-providing PACE services. He further explains the issue is more federal, “the state would love to have more PACE providers but there are large barriers to becoming a PACE provider” further stating, “you [the provider] must build a significant infrastructure before you can take your first client so there are large barriers to entry as providers” (McCormick, 2017).

With further research, the barriers for becoming a PACE provider are evident. CMS provides the PACE provider application online, the application is over 30 pages long and

includes ten major sections related to topics such as finance, marketing, quality assessment, services provided, and more (Centers for Medicare & Medicaid Services, 2012). Each provider must begin with a description of the organization, a profile of their patients served and how many of those patients should be PACE participants. Then, the application continues on each provider must answer ten chapters of questions with multiple subsections in detail (Centers for Medicare & Medicaid Services, 2012).

When asked about beneficial alternative programs offered in Oregon for HCBS McCormick explained Oregon has the 1915k community first choice option as the largest way Oregon residents receive HCBS. He explained it has worked well for Oregon but does not know how well it would translate to other states. The Oregon DHS website explains the 1915K plan, “It allows states like Oregon to provide home and community-based services and supports while receiving a six percent increase in federal medical assistance funds from the federal government for those services” (DHS, 2017). The services provided allow Oregon residents assistance with ADLs and IADLs in their home, allowing them to live safely and independently for longer. As for eligibility for the 1915k waiver, DHS explains, since it is a Medicaid waiver plan, the recipient must be a Medicaid enrollee. Furthermore, the enrollment for 1915k is the same for all the other waiver programs, as part of the Oregon Medicaid person centered planning, a participant will be given a functional needs assessment. To enroll the participant must meet the criteria of an institutional level of care, then, when a need is determined the participant is matched with a provider, then the services may begin (DHS, 2017).

Hittle further explained when the Money Follows the Person program was abandoned Oregon’s efforts shifted toward the 1915k community first choice option plan, the funds raised from this are utilized to help shift residents from institutions to community based services

(Hittle, 2016). Hittle went into further explanation of the 1915 waiver's Oregon is involved in, stating, "Oregon is robust in home and community based services, first the 1915c waiver back in the 80s for aged and physically disabled was introduced, then for people with intellectual disabilities. Now, there are 6 different components of the 1915 waiver" (Hittle, 2016). The 1915k was approved in July of 2014, expanding HCBS throughout the state (Hittle, 2016). The 1915k has been great for HCBS in Oregon, increasing the federal matching up to 6% for home and community based services.

Bartholomew explained "Oregon Project Independence" (OPI) as another transitioning program unique to the state. The goal of the project is to get ahead of the Medicaid population, by going out to the pre-Medicaid target population and installing precautionary elements to help them remain in their home. Bartholomew explains the project's goal is to provide home care services that will hopefully prevent pre-Medicaid population from needing Medicaid and keeping them healthier and safer in their own homes. Some of the services OPI provides include, "housekeeping, respite for family caregivers, ramp installation, grab bars, medical equipment, etc." (Bartholomew, Interview, 2016). Many enjoy the project and the state advocates for it rigorously, with the hope that if they can invest money in now it can help the pre-Medicaid target population from ever becoming Medicaid eligible, saving money for the state in the future. The program has been around for over 20 years and struggled to stay afloat during the recession, Bartholomew explained there were times when the program was completely defunded but still has managed to remain.

Through further research on the state website the program reveals why it is so valued by consumers, "OPI is a program providing a variety of services to Oregonians age 60 and older who do not receive Medicaid services. These services are intended to support their independence

and allow them to remain in their home as long as they wish” (NorthWest Senior & Disability Services., 2017, p. 1). Mr. Bartholomew spoke to the OPI largely for how Oregon advocates more for HCBS over institutional services. A “NWSDS Case Manager” who ensures the person is over the age of 60 and needs some type of in home assistance, which is done through an assessment by the case manager, determines eligibility for OPI. There is an exception to the age requirement; someone under the age of 60 may enroll for OPI if they have either Alzheimer's or dementia (NorthWest Senior & Disability Services, 2017). Many services are offered to OPI participants, and the level and mix of services is personalized for each participant. Bartholomew mentioned the program is beloved mainly because services offered are not strictly medical. OPI offers assistance with, “chores, home delivered meals, case management, information and assistance, outreach, respite, interpreting/translation, and money management” (NorthWest Senior & Disability Services, 2017, p. 1). OPI has given ability for Oregon to recognize a non-Medicaid eligible population and provides them assistance with activities of daily and living and independent activities of daily living allowing larger percentages to age in their home receiving care unique to their needs. When asked about the reasoning behind OPI Bartholomew explained, “the goal is to have a lower cost program from preventing people from being Medicaid eligible. If people aren’t burning through their own resources they will stay off Medicaid longer, which is good because Medicaid is expensive” (Bartholomew, 2016). The services are paid for by participants through a five-dollar fee per year along with a monthly fee, which is determined by the participant’s income level and number of services they require. (NorthWest Senior & Disability Services, 2017).

Emotional Significance

The next section of the interview related to emotional significance of HCBS. Both Bartholomew and McCormick felt Oregon has a lot of work to do when it comes to the emotional significance areas, specifically with helping caregivers providing LTSS in the home. Despite ranking in the second quartile for support for family caregivers he notes caregiver stress is an element Oregon is actively working towards bettering the emotional aspects to aging in place. McCormick highlighted the caregiver stress metric is something the state is actively working towards advancing. McCormick explained Oregon does not have a lot of programs to support their informal caregivers and DHS is involved with AARP to come up with possible informal caregiver respite service programs. McCormick explained DHS and AARP have a workgroup of about 20 people trying to come up with a proposal for respite service programs for the next legislative session (McCormick, 2016). Overall, Oregon addresses this is an area for improvement and is working across state departments to come up with programs and support for informal caregivers.

Bartholomew mentioned the Aging Disability Resource Connection (ADRC), which is an informational referral service. Caregivers can utilize the ADRC to explore different options for LTSS and what is the best option for their loved one. Furthermore, Oregon has training programs for caregivers. Oregon has supplemented funding to these programs which work to provide in person and online training around the state, one immediate limitation to the training sessions have been finding someone to watch their loved one so the caregiver can attend the training sessions. When asked about barriers to the training programs Bartholomew jumped directly to funding. Oregon has “senior medical deduction” a unique program that allows seniors to deduct medical expenses on their state tax returns (Hunsberger, 2015).

Bartholomew mentioned there were some issues with the medical deductions at the start and the system was being abused. He gave a hypothetical example where someone over the age of 62, married to someone much younger, could deduct cosmetic surgery expenses simply because their spouse fell into the correct age category (Bartholomew, 2016). The program has become more restrictive and now you must be 63 to deduct medical expenses, by 2020 the age will increase to 66 (Hunsberger, 2016). Furthermore, there is a cap for how much can be deducted per senior. Hunsberger explains the caps as, "...\$1,400 for singles with adjusted gross incomes between \$25,000 and \$50,000 and joint filers between 50,000 and 100,000" adding, "the cap dropped to \$1,000 for singles with AGIs between 50,000 and 100,000 and joint filers between 100,000 and 200,000" (Hunsberger, 2015, para. 4). The adjustments seem to address the issues first highlighted by Bartholomew. Since the money was being deducted from senior's expenses and many advocates felt as though that money should be redirected back to benefit the senior population. Bartholomew stated legislators agree to utilize half the deduction money on the senior population, this funding could then be directed into programs such as OPI and funding the training program. Bartholomew reported there was around 26 million dollars to be utilized on the training program and other home and community based services from the tax deductions. (Bartholomew, 2015) Overall, the Oregon interviewees note's work to be done but the funding and advocating for HCBS remains constant and improving without the threat of switching towards institutional funding any time.

Bartholomew mentioned how emotional wellbeing is an area Oregon feels they need improvement in and not having a specific program designed to measuring and collecting specific data on the emotional wellbeing. He explained Oregon focuses on it through each program they have developed. For example, in the training programs, emotional stress is a common element

brought up by participants and the information can be utilized to improve the training programs for the future. McCormick supported the response from Bartholomew stating Oregon does not have any plans to create a program targeted at observing the emotional wellbeing of elderly citizens in community based care or institutional settings. Oregon focuses on the emotional aspects through offering well-rounded, patient centered care. Furthermore, McCormick did not believe there would be barriers to implementing patient direction programs, Oregon is moving to provide patients as much independence as possible so patient direction programs are the focus of their efforts. Hittle directed this section of the interview to McCormick's responses, explaining DHS focuses more on the operational elements of the programs being introduced for informal caregivers and emotional support adding, the 1915 waivers are patient centered and evaluations are done with the patient's best interest in mind.

General

The final section of the interview addresses general programs or elements not answered thus far. Bartholomew mentioned a patient directed program through the Oregon Home Care Commission (OHCC). Bartholomew explained the OHCC set up a registry where both healthcare workers and consumers can submit profiles; the registry then matches the best worker and consumer for home care. The OHCC is a consumer-centered model, the person can enter the services they would like and how often they would like them to come, then the registry matches them with a worker. The system is set up for private pay individuals and allows the consumer to have a hand in who their home health care is provided by. Bartholomew explained the program gets back to Oregon's "mantra" of independence, choice, and dignity, allowing both caregivers

and consumers to have specialized schedules meeting their unique needs. The specialization allows for consumers to feel independent and caregivers to feel valued and responsible.

Hittle, when asked about patient direction programs mentioned all elements in the 1915c waiver are self-directed. The 1915 c waivers are the Medicaid Home and Community Based Service waivers, states with the waiver must show the services provided through the waiver will not cost more than in an institution, must show the people's health and wellbeing are protected, and the services are individualized and centered around each patient (Medicaid, 2017a). There were no main barriers associated with the changes in the 1915 waivers when the 1915k waiver was introduced. When asked about programs targeted at observing the emotional wellbeing of the elderly in HCBS or institutional settings she explained, CMS partners with the Oregon health authority, describing the partnership as, "the behavioral health and Medicaid state plan partner on a number of programs to bring enhanced care programs in AP licensed facilities" (Hittle, 2016). The coordinated care organizations are also unique to Oregon the CCO is supposed to work with local field offices to make sure all levels of care are met for elderly, including physical, mental, and behavioral aspects (Oregon Department of Human Services, 2017b).

Oregon ranks third in the country on AARPs State Scorecard Summary of LTSS System Performance Across Dimension. Through interviews with Bartholomew from AARP, McCormick from DHS, and Hittle from CMS I was able to collect valuable information into the rebalancing efforts of Oregon and some of the reasons behind their success. Oregon utilizes about 70% of their LTSS budget for HCBS and all parties agree the funding for HCBS will only increase especially as the population ages. Bartholomew had vast insight into Oregon's unique plans such as the Oregon Independence Project, which seeks to provide HCBS to the pre-Medicaid population through small weekly copays and monthly fees based on income level and

services required. McCormick explains the expansion of the All Inclusive Care for the Elderly--PACE program.

For Oregon, all three departments interviewed work very closely on programs and advancements for HCBS. AARP and DHS have a group creating a proposal for respite service programs for informal caregivers for the next legislative session. Additionally, Hittle mentioned the Medicaid department is a sister agency with aging in DHS so the budget and planning is all coordinated. Oregon has a mantra by which their LTSS are delivered with the goal of keeping people independent, with dignity, and providing them with choices. Oregon recognizes their areas for improvement as providing resources to informal caregivers. A major barrier highlighted in the interviews is funding, and federal regulations. McCormick believes the reason PACE cannot expand more quickly is due to the federal regulations for becoming a PACE provider. The application for becoming a provider is over 30 pages to begin, then each applicant must provide detailed explanations related to financials, market share, possible PACE users, and more. Through speaking with state representatives it was apparent the departments all want to create more programs and better care for LTSS users and family caregivers, however, state funding can only go so far. Oregon has come up with unique ways to divert funds towards state programs such as the medical tax deductions for seniors that can then be directed to training programs and adult day care center operations. However, a large barrier noted is a lack of finances to fund and expand HCBS programs. Overall, Oregon works with patient centered, home and community based ideas and their budget allocation and rank in the scorecard matches their mantra and goals.

Chapter 4

New Jersey

Background

New Jersey ties for 26th with Montana on the AARP State Scorecard Summary of LTSS System Performance Across Dimension. New Jersey is in the first quartile “affordability and access”; the third quartile for “choice of setting and provider” and “effective transitions”; the second quartile for “quality of life and quality of care” and “support for family caregivers” (AARP scorecard, 2014). The New Jersey Department of Human Services (DHS) explains when Medicaid was created by congress the major way disabilities were treated was through institutions and now, the push is to provide as many services within the community and in the home. The website cites different 1115c waivers that are explained in more detail below. New Jersey programs focus on not just providing medical services such as skilled nursing and dental in the home, but also non-medical services such as home modifications and respite care all with the goal of keeping people out of institutions for as long as possible. (State of New Jersey Department of Human Services Division of Disability Services, 2017a).

Nancy Day and Laura Otterbourg spoke on behalf of the division of aging services in DHS and the Medicaid advisory council through New Jersey’s Managed Long-Term Services and Supports (MLTSS). New Jersey’s aging council through DHS and Medicaid are sister agencies, and Day spoke on behalf of both departments with her colleague Otterbourg. New Jersey state resources are utilized to further supplement the interviews.

Cost Effectiveness

To begin the interview, I asked about the division of funding towards HCBS versus institutional based services. For a six-month period, Day explained, “\$2 billion are allocated to LTSS, \$821 million is given to institutional services” (Day, 2016). Therefore, \$1,179,000,000 is left for HCBS through calculation I determined the majority of the budget, 58.95%, is devoted towards home and community based services. Day further explained for patient enrollment, there has been a 42% increase to home and community based settings rather than institutional. This is a large increase from 2014, when Managed Long-Term Services and Supports (MLTSS) began; the enrollment was only 28% to HCBS. Overall, New Jersey as a state recently is advocating more for HCBS as evident of their funding and shifting of enrollments. Day highlighted, while the state advocates for HCBS nursing facilities will always be important, and while both the state and residents prefer to remain in their community they need to ensure they are receiving sufficient support and at times, the nursing facility is the safer option (Day, 2016).

Transitioning

Next when asked about, and the Money Follows the Person demonstration, Day explained the program started in New Jersey in 2007. The program is also called “I Choose Home” in New Jersey. Upon further research, it is a federal program with two main goals expressed, “move people out of nursing homes and developmental centers back into the community and re-invest Medicaid dollars saved back into home and community-based services to grow the system” (State of New Jersey Department of Human Services Division of Disability Services, 2017a, p.1). To be eligible the participant must have been in an institution for over 90

days, must be a Medicaid recipient, and be able to move into a home or community setting where there will be support for them. The first year of the program, when a New Jersey resident was transitioned, the state received a federal match, which was then reinvested into the program to help others transition. New Jersey has great success with the program, transitioning over 1,800 people with goals to reach over 2,200 by the year 2020. If the goal is reached, the program will have resulted in over \$35 million of cost savings for New Jersey (State of New Jersey Department of Human Services Division of Disability Services, 2017a).

Day explained with the Money Follows the Person demonstration is beneficial because the staff work with the individual to ensure they have a safe place to live, with proper equipment and services to ensure a smooth transition (Day, 2016). New Jersey DHS highlights that even if a person does not have their own home to move into, social workers can work with local housing authorities to search for affordable options while also helping furnish the home and other start up expenses (State of New Jersey Department of Human Services Division of Disability Services, 2017c). Day explained, the staff helps the individual put things the way they should be in order to provide the person the best possible living situation.

New Jersey is involved in the Balancing Incentive Program (BIP). DHS posts, “New Jersey was awarded with \$108.5 million from the US department of Health and Human Services, Centers for Medicare and Medicaid Services, to support the expansion of home and community-based services for New Jersey seniors and people with disabilities” (State of New Jersey Department of Human Services Division of Disability Services, 2017c, p.1). The money has allowed for New Jersey to recuperate and build upon the home and community based services. Day explained the enrollment in the BIP allowed for the creation of a single point of entry, the program is responsible for over 20 counties in New Jersey as Aging & Disability Resource

Connection (ADRC) resources. The no wrong door system allows one place for people to find a multiple of information sources regarding long-term care services in New Jersey. New Jersey's single point of entry allows citizens the ability to find websites, toll free phone numbers, and access to local agencies easily (Day, 2016).

Day also brought up the usage of a standardized assessment; with further research the assessment looks into items such as ADLs, IADLs, medical diagnoses, cognitive levels, and behavior characteristics. Each of the areas has specific topics which the assessment focuses on (Balancing Incentive Program, 2017). Day states, "Conflict free case management is authorized for 38 counties" (2016). Resources explain conflict free case management as the case manager not being financially, clinically or otherwise related to the person in context (Notarstefano, 2017). Furthermore, the assessments check to see if a person meets the requirements of a nursing facility level of care and is in fact a state resident. The person is then either approved or denied, and if they are determined to not require a nursing facility level of care set by PACE, another assessment will be conducted to be sure (Day, 2016). Finally, Day highlights no person may be denied because their care may be too costly (2016).

PACE is a large part of New Jersey's LTSS network, in 2010 the state had only two PACE sites, however when speaking with Day, she explained there are five sites. There are 900 enrollees per site and by late spring Day expects more PACE providers to open in new places throughout the state. Further information provided on the New Jersey DHS website explains the Medicare program in detail and its history in New Jersey. DHS explains to participate in PACE in New Jersey, "an individual must be 55 years of age or older, require nursing home level of care but be able to live safely in the community at time of enrollment with services of PACE, and reside in service area of a PACE organization" (State of New Jersey Department of Human

Services Division of Aging Services, 2017b, p. 1). New Jersey began PACE in 2009 with two agencies, a third opened in 2010, followed by a fourth in 2011, and finally a fifth in 2015. In 2004, New Jersey was given a grant from CMS, the money was utilized to determine the best locations for new PACE sites and to conduct outreach to community members and providers about the program specifics (State of New Jersey Department of Human Services Division of Aging Services, 2017b).

Emotional Significance

Day stressed New Jersey's focus on programs available for informal caregivers. New Jersey has a 'Statewide Respite Care Program (SRCP)'. Day explained the program has help put New Jersey in the forefront of offering state funded programs for informal and unpaid caregivers. The New Jersey government describes the program as one to provide services such as; "companion, homemaker/home health aide, social or medical adult day health care, private duty nursing, adult family care, in-patient care, campership, and a consumer directed option" to caregivers who provide daily care to elderly and impaired adults (Seaman, 2017). To be eligible for the program, the caregiver must be receiving no pay for the care they are providing to a loved one over 18 years with a chronic disability, either physical or mental. Furthermore, the financial requirements are such that, "[the] care recipient must have income at or below \$1,869 per month (\$3,738 for couples), and have liquid resources of less than \$40,000 (60,000 for couples" (Seaman, 2017, para. 4). Day further explained the benefits to the program by explaining if a family caregiver needs to go away for the weekend this program can help provide a caregiver for the time they are away. Day mentioned the program has been around since 1986 or so and has

been enjoyed and improved over the years. The program helps with the everyday stress an unpaid caregiver faces (2016).

Another program designed to help with informal caregivers is the Alzheimer's Adult Day Health Services Program (AADSP). The program is described by the state as a program that, "partially subsidizes the purchase of Adult Day services for person's with Alzheimer's dementia or related disorder. Adult Day Services provide respite to family caregivers as well as therapeutic care for older adults with memory loss" (Wilson, 2017, para. 1). Day explains, "the program provides an average of 2-3 days of medical or social day care [a week] for those diagnosed with dementia" (Day, 2016). The caregiver is then able to have respite during the hours of the day where their loved one is at the care center. The program has been around since the early 1980s expressing its importance to the state (Day, 2016). The requirements for the program are that the New Jersey resident must have an Alzheimer's or dementia disorder and reside in the community of the program, furthermore, the participant must have an informal caregiver that cares for them regularly. As for the financial requirements, "Income cannot exceed 600% of SSI (individual) or 700% (couple) and resources cannot exceed \$40,000 (individual) or \$60,000 (couple)." (Wilson, 2017, para 3). The program consists of 48 centers serving 19 counties in New Jersey (Wilson, 2017).

Next, Day explained the Jersey Assistance for Community Caregiving (JACC), which is a state funded program and provides training for caregivers. The Department of Human Services further explains JACC, "a State-funded program that provides a broad array of in-home services to enable an individual, at risk of placement in a nursing facility and who meets income and resource requirements, to remain in his or her community home..." (DHS, 2017, para 1). JACC offers many services and are decided jointly by the participant and their case manager through a

clinical assessment and ‘Plan of Care (POC)’ (DHS, 2017). Services include but are not limited to, “respite care, attendant care, caregiver/recipient training, home delivered meal service, etc.” (DHS, 2017, para 3). As Day explained this program is one that offers training help to informal caregivers along with providing respite services. DHS highlights there are caps for certain services and an individual may only receive up to \$600 worth of services per month (DHS, 2017). JACC is not a Medicaid program and serves those who do not qualify for Medicaid. To be eligible for JACC a New Jersey resident must be 60 years or older, live in their own or a loved ones home, have no other ways of obtaining needed services and has been assessed as eligible for nursing facility care levels (DHS, 2017). JACC provides New Jersey with a unique way to utilize state funds to train informal caregivers while also providing services to elderly and disabled.

New Jersey has a variety of unique programs to provide respite and training to informal caregivers. New Jersey ranked in the second quartile on the AARP scorecard for ‘support for family caregivers’ Day feels the state is at the forefront for state funded programs for informal caregivers (2016). Further information allowed for explanation of the Statewide Respite Care Program, the Alzheimer’s Adult Day Health Services Program, and the Jersey Assistance for Community Caregiving program. These programs are unique to New Jersey, the SRCP and AADHP have been active since the early to mid-1980s and have been appreciated for many years.

General

When asked about other programs New Jersey offers in terms of HCBS, Day explained there are multiple MLTSS waivers encouraging HCBS. For example, New Jersey has a GlobalOptions (GO) program that was one of four projects to be consolidated in 2014 and moved under the MLTSS program. Day explained, in July of 2014 four programs were moved to the managed long-term service and supports 1115 waiver. The goal being to get home and community based services under MLTSS to coordinate programs and services better.

Chapter 5

Kentucky

Background

Kentucky was selected as the low performing state for the study. Kentucky ranked in the bottom quartile for all five categories, scoring 51st out of 51 states in the AARP LTSS state scorecard. I was able to speak with a contact from AARP, the Department for Aging and Independent Living (DAIL), and CMS. Kentucky's cabinet for health and family services, under the department of Medicaid services, explains Kentucky's Medicaid programs including their Long-Term Care and Community Alternatives. Kentucky lists two main sections for long-term care services, which are the "Intermediate Care Facilities for Individuals with Intellectual Disabilities "and" Nursing Facility," (DMS, 2017a). The first highlights how KY Medicaid covers services for citizens with an intellectual disability requiring inpatient treatment, the state highlights the requirements for those who are eligible, furthermore, the services are typically provided within a facility but the state highlights Medicaid Waiver services for those who wish to stay in the home.

There are seven waivers for Kentucky citizens requiring LTSS but wishing to remain in their home. The waivers are further explained in the transitioning section below. The AARP scorecard highlights Kentucky fell lowest in three areas, "Affordability and Access", "Choice of Setting and Provider"; and "Quality of Care and Quality of Life" ranking 51st, 50th and 50th

respectively. The following sections will better explain Kentucky's long-term care and ranking on the scorecard (AARP, The Commonwealth Fund, & The Scan Foundation, 2014).

Cost Effectiveness

Kentucky devotes a larger portion of their LTSS budget towards institutional based care than home and community based. All parties interviewed agree the percentage was close to 80% of the budget towards institutional care, Gresham in the department of Medicaid services reported for 2014 Kentucky spent about \$709 million on their home and community based waiver expenditures and for 2016 they increased the total dollars spent on HCBS however, the funding still was much higher for institutional based settings. Evans, from AARP, explains while funding makes it seem Kentucky advocates more for institutional based care, there is a large push for home and community based services. Especially from the community and organizations such as AARP who deal with the recipients of LTSS on a daily basis and are constantly made aware of their needs and preferences for receiving care (Evans, 2017).

Gresham, of Medicaid services, further explains the divide in advocating and funding allocation, explaining the most current and vocal advocates are speaking on behalf of more home and community based services. However, Gresham notes there is a large nursing facility lobby platform in Kentucky that has been active in the state for a long time now. Gresham explains the majority of current efforts for LTSS is to reform the state waivers and provide services to best-fit state resident's needs. Wells, further supports the responses from Gresham and Evans explaining while it looks like Kentucky advocates more for institutional based care, based off funding allocation, agencies would rather have people in the community for two reasons, cost

effectiveness and citizen's preferences. Wells, and the Kentucky governmental departments associated with long-term service supports, recognize the cost effective benefits of HCBS along with understanding state residents likely prefer to age in the comfort of their own community. As for future funding, Wells believes Kentucky will be working to keep people in the community, explaining the state is working to find other avenues for caregiving than just family members. Wells explains Kentucky is working on pilot programs for presumptive eligibility. However, both Gresham and Evans believe the funding allocations to remain the same. Gresham states Kentucky has no immediate plans for closing any nursing homes and nursing homes have been a large part long-term care delivery in the state's history. Gresham does believe Kentucky will work to balance funding but will do so mainly through the federal final rule waivers, making services better and helping state residents utilize the waivers more. Gresham recognizes Kentucky will need more of a culture change to see shifting in funding for long-term care services. Evans, like Gresham does not believe there will be much shift in funding at least in the near future. He explains the Governor made more HCBS openings but not enough to make an impact on the people wanting and waiting for the slots. Evans believes Kentucky is working in the correct direction but there is more for significant change.

Transitioning

Kentucky created "Kentucky Transitions" a Money Follows the Person demonstration in 2008 (Gresham, 2017). The program began by serving intellectually disabled (IDD), physically disabled, those with acquired brain injuries, and those with mental illnesses. There are distinct 1915c waivers for each population; Gresham explained the first is the supports for community

living waiver, which is for those with intellectual disabilities. Upon further research the supports for community living waiver is a home and community based waiver funded through Kentucky Medicaid and serves as an alternative for institutionalization for those with intellectual disabilities requiring help with activities of daily living (Blackwell, 2015). Similarly, the acquired brain injury long- term care waiver allows for those who have reached their maximum potential in their rehabilitation to live in the community safely through a multitude of programs including but not limited to, “case management, respite care, supported employment, occupational therapy” (Division of Community Alternatives Acquired Brain Injury Branch, 2016, p.1). The other waiver programs are all similar with providing programs aimed at assisting families with their loved ones requiring help in activities of daily living and independent activities of daily living. The programs allow for Kentucky residents to receive care they will require for the rest of their lives in their home for as long as safely possible (Division of Community Alternatives Acquired Brain Injury Branch, 2016).¹

Gresham explains the Kentucky transitions program has allowed for over 600 people to move from an institution back home for care, and has pushed the state and Medicaid to look at their institutions in a “different light” resulting in changes to benefit residents (Gresham, 2017). Gresham stated the transitioning piece of the waivers has encouraged Kentucky to reevaluate other waivers to see if transitioning can be implemented. While Gresham believes the money follows the person demonstration is beneficial and well utilized, Evans of AARP, sees it as an underutilized program and transition in general needs improvement. Evans believes working with family caregivers and finding a way to educate and train informal caregivers to provide care in the home would be a more affordable and appreciated option for people who require LTSS,

¹ See appendix B for full description of seven Kentucky Medicaid Waiver Programs

explaining the average cost of institutional care is \$46 thousand, which is twice as much as the average income (Evans, 2016). Evans believes that when those with Alzheimer's and dementia are moved in and out of institutions have worsened symptoms. Wells, through working closely with the Medicaid department has seen the utilization of the Kentucky Transitions program and recognizes barriers to implementation. She explains housing is the largest barrier, people who could live in the community and do not need institutional level care are still forced into institutions because there are no homes or support for them in their community. Kentucky's results with the program are good because the people who are able to transition do well in the community and do not need to return to the institution. Personal care homes are considered institutions and assisted living homes are not reimbursed by Medicaid so are only available for private pay individuals, creating barriers to entry and utilization.

Kentucky is also involved in the Balancing Incentive Program (BIP). Wells explained the program's main utilization of funds to create, "a unified system and Medicaid waiver application system, trying to create a single point of entry for applicants" (Wells, 2016). Gresham further explains the funds for the BIP allow for data collection on the possibility of an assessment tool for waivers that would help the Medicaid department to process waivers more uniformly. Further research explains the strategic initiatives with Kentucky's implementation of the BIP. There are five structural changes including, "no wrong door/single entry point, informative CHFS CB-LTSS website, initial assessment, core standardized assessment (CSA) instruments, conflict-free case management" (Crane & NASUAD, 2014). Gresham further explained the BIP funds are helping to better utilize the "Benefind" program as the no wrong door point of entry and further expanding the arms of the program (Gresham, 2017). Benefind is a public assistance program that aims to, "build strong families and obtain services such as food, cash and medical assistance

to become self - sufficient” (DCBS Family Support, p. 1, 2017). Benefind helps families determine their eligibility to specific programs and while not directly related to LTSS the BIP funds can help families enroll for assisting programs that could provide some respite to possible home caregivers. When PACE was brought up in the interviews all three contacts explain Kentucky is not interested in the program at the time. Wells explained Kentucky is hesitant to follow and do what other states are doing and PACE is not a priority at the time for Kentucky. Kentucky has a few other transitioning elements and programs such as the presumptive eligibility and reevaluating waivers for Medicaid populations (Wells, 2016).

Overall, Kentucky utilizes the 1915c waivers as the main method for transitioning elders to home and community-based services, and for HCBS in general. The Kentucky transitions program is Kentucky’s version of the MFP and while it has transitioned over 600 citizens, Evans from AARP believes it is underutilized. Gresham explained transitioning could be utilized in other waivers to help utilize more HCBS. The BIP has allowed Kentucky to create a single point of entry and unified waiver application system. Furthermore, Benefind, within BIP helps families determine eligibility status for specific programs. Kentucky does not participate in PACE and is focusing more on reevaluating and utilizing their waivers.

Emotional Significance

Kentucky falls in the bottom quartile for AARP’s Long-Term Services and Supports scorecard for ‘Support for Family Caregivers’, Wells explains Kentucky does not have any caregiver specific programs within the home and community based waivers, further stating, some of the waivers have family training available to them but do not have caregivers in waiver

programs. Wells further explains Kentucky does not have caregivers involved in the waiver programs therefore they are not able to take advantage of the education and support training available for them, since there is not a basis of the waivers being accessed to their full potential. Well sites it is hard to justify creating new support programs for family caregivers (Wells, 2016).

Gresham further explains the waivers role in the emotional aspect for Kentucky. Gresham explains that all waivers expect one have a patient direction service option (PDS) that allows family members and other non-formal caregivers can enroll to provide care. However, Gresham explains the barriers to the waiver PDS option. For example, there are pre-employment costs such as drug tests and background checks that many informal caregivers list as a barrier to enrolling. While Gresham notes it is a small barrier there are a number of advocates that explain the pre-employment costs detract from the availability of caregivers. Another barrier to the ability for informal caregivers to enroll in waivers through the PDS option are the possibility of exploitation of the family member needing LTS. Gresham notes these are not common instances but they do occur (Gresham, 2017).

Evans explains there is a current Kentucky family caregiver act going through legislation that would require hospitals to give live demonstration to the person being discharged and their caregiver on the elements they will need for their care. The bill has passed the state's house but not the senate, and the delay is expressed as a barrier from Evans to providing a training program to informal caregivers (2016). The act would require the hospital to contact the caregiver in advance if their loved one would be switched to a nursing home and the family would be required to include them on the medical journey of their loved one. The act would help both recipients and caregivers feel more comfortable, and be more prepared upon discharge to their

home. The barrier to Kentucky family caregiver option is the legislation and the time length that goes into it a vote between the house and senate (Evans, 2016).

General

Kentucky has several elements related to patient direction and other elements to HCBS not discussed thus far. Wells explains both state funded programs and Medicaid waivers have patient direction programs. Wells notes patient direction programs are “booming” and all waivers include patient direction elements and there has been an increase for self-direction within community integration. Wells notes healthcare is shifting to giving people control, and with the waivers she has noticed it specifically in participants picking their employees. The largest barrier has been the employees, and the costs associated with background checks. The state needs to ensure they are hiring safe and appropriate caregivers through patient direction programs however, some caregivers note issues with paying for the background checks and training components. Furthermore, Wells explains the waivers and state funded programs have a survey for all participants. The surveys collect an array of information and some of it relates to the emotional well-being of those receiving HCBS. Wells admits as of recent the data is just being collected, and not much is done after collection, however, the initial step is there. Also, caseworkers oversee the surveys to ensure no participants are having issues, and if they are they receive the proper referrals, be it mental health, safety issues, etc. The survey is conducted to those within institutional care but is also utilized in HCBS (Wells, 2016).

Greshman notes additional programs targeted at the emotional wellbeing of elders but most of them are through institutional settings. For example, within nursing facility care there are screenings for mental illnesses and intellectual and developmental disabilities, the screening allows for those in the nursing facility to be assessed and a care plan to be created best fitting the needs of the patient. Greshman also explained the community mental health centers through state funds have been able to provide “targeted case management for people with [serious mental illnesses] SMI” (2016). Finally, Greshman explained within the last year or so Kentucky has started a behavioral health piece with over 40 new regulations targeting behavioral health and substance abuse issues for the Medicaid population, which includes elderly Medicaid participants. While the elderly are not specifically targeted, Greshman notes there could be benefits to the regulations and elder population (2016).

Evans, of AARP explained there are not many programs an agency such as AARP can provide in terms of patient direction. However, he did explain the prepare to care program within AARP which essentially addresses “creating your own team” and understanding the protocols and precautions you as an aging adult can partake in to help your family. Evans explains the program encourages those entering into their elder years to plan ahead and write down and inform family about important financial information, care guidelines, and more. There is an online program that caregivers may download and prepare for dementia issues their loved one may face and important steps to take leading up to becoming an informal caregiver. Furthermore, Evans explains respite care is a large issue for Kentucky. Adding, “the state needs to do better on family leave, they need to come up with a law that exceeds federal laws on family leave” (Evans, 2016). Evans is a lobbyist and constantly looks for ways to change the state government perspective. He states the state agency on aging and area agencies on aging are the areas to focus

in to get family caregivers more help. He sees a large gap in respite care services and caregivers who are financially stretched thin because they spend a large amount of their time providing care where they do not receive adequate compensation. Evans understands Kentucky is working towards developing more patient direction programs and emotional support programs but has work to do. Evan stresses the importance of changing the government mentality of long-term care through advocating and lobbying of HCBS.

Kentucky is working on elements of patient direction programs and ways to monitor the emotional wellbeing of those receiving long- term care. As of now there are several programs or monitoring mental and emotional wellbeing of citizens but they are geared mainly towards nursing facilities and institutions and are not utilized by home care services. Furthermore, the waivers contain the most patient direction program options. Kentucky Medicaid has developed a behavioral health element that focuses on substance abuse and behavioral health issues for the Medicaid population that could benefit the elder population while it is not their direct target.

Chapter 6

Results

Introduction

The study sought to observe and analyze three elements of rebalancing long- term care within three states with the hope of determining commonalities for current and future funding for rebalancing care, along with barriers to rebalancing. All three states believe home and community based services are the future of long-term care and what aging citizens in their states prefer.

Cost Effectiveness

All three states allocate separate proportions of their budget towards home and community based care, shown in table two below. Even with the vast difference, especially between Oregon and Kentucky, all three states recognize the cost effectiveness of HCBS. Both Oregon and New Jersey interviews revealed shifting more of their budget towards HCBS and away from institutional settings. Oregon mentioned attempting to rid institutional care wherever possible. However, both Kentucky and New Jersey highlight the importance of institutional based services to their citizens and the need for funding these programs. After the interviews and research, it became evident that the state's ranking on the AARP scorecard correlates with funding towards HCBS. Through interviewing it became evident that the higher ranking the state, the more money allocated from their LTSS budget towards HCBS.

Table 2 Funding Percentage Per State

	Oregon	New Jersey	Kentucky
Institutional	30.9%	41.5%	80%
Home and Community Based	69.1%	58.95%	20%

Transitioning

Again, each state participates in different transitioning programs for their residents to move from institutional to home and community-based settings. However, all states offer some form of transitioning programs and have met success with such programs. Depicted below is a table of the common transitioning programs utilized between the three states. Furthermore, Oregon offers the 1915i community first choice option through Medicaid and the Oregon Project Independence. While OPI is not specifically a transitioning program it represents a program aiming to keep residents from ever needing to enter an institution and keep them in their homes

for LTSS. Additionally, Kentucky utilizes the 1915c Medicaid waivers and within the BIP they created Benefind.

The table displays that both New Jersey and Kentucky utilize the Money Follows the Person program and have had varied success levels. “I Choose Home” the MFP program of New Jersey has led to transitioning over 1,800 people so far with hopes of reaching over 2,200 by 2020 (Day, 2016). Day added New Jersey has had \$35 million of cost savings through their “I Choose Home” program (Day, 2016). Kentucky interviewees had differing opinions on the success level of “Kentucky Transitions” their MFP program. Gresham explains over 600 people have been transitioned within the state and sees the program as a success, however Evans, of AARP sees it as an underutilized program and recognizes room for improvement (2016). Oregon abandoned the MFP after realizing the program was regulation heavy and did not meet the needs of Oregon residents because they are already well balanced (McCormick, 2016).

New Jersey and Kentucky also participate in the Balancing Incentive Program and have used the governmental funds to create no wrong door processes for their long-term care information. Additionally, New Jersey has used the funds to create standardized assessments and conflict free case management. Kentucky used their funds to invest in Benefind, their no wrong door point of entry that helps families’ assess their eligibility to specific state programs (Gresham, 2017). Both New Jersey and Oregon participate in PACE, Oregon explains some adult day care centers partner with PACE to stay open, considering adult day centers do not accept Medicaid. Furthermore, Oregon interviews revealed an overall positive outlook on the PACE program. Issues to becoming a PACE provider were highlighted as a barrier in Oregon interviews (McCormick, 2017). New Jersey’s PACE program is expanding; in 2010 they had only two sites and now there are five sites with over 900 enrollees per site (Day, 2016).

Emotional Significance

Each state has their own programs focusing on the emotional support towards elders and disabled and their caregivers. While there were no overlapping programs that all states participated in, all states mentioned programs targeting emotional elements of aging and disabilities. Furthermore, all states recognize this as an area needing improvement. Oregon offers a tax deduction for senior's medical expenses that is then funneled back into providing them additional care. While this may not seem like a direct emotional support program, it is another program Oregon created to benefit their seniors. Another program is the Aging Disability Resource connection, an informational referral service that allows elders and their caregivers to explore different LTSS options. The ADRC also offers training programs for caregivers (Bartholomew, 2016). Finally, unique to Oregon is the Oregon Home Care Commission, which is a patient directed program where both healthcare workers and consumers submit profiles and are able to match better based on care levels required and personality traits.

New Jersey explained they are at the forefront of offering state funded programs for informal caregivers. The Statewide Respite Care Program offers ADL and IADL services to those over 18 years old with a chronic disability, allowing loved ones a break in providing care. Furthermore, New Jersey offers the Alzheimer's Adult Day Health Services Program, which Day described as providing 2-3 days of care, medical or social, a week for those with dementia, giving the informal family caregiver respite (Day, 2016). Next is the Jersey Assistance for Community Caregiving, a state funded program that provides training and respite services for informal caregivers and pairs the participant with a case manager (Day, 2016).

Kentucky did not have any specific caregiver programs. The main way emotional support is provided is through the Medicaid waivers. Kentucky has pending legislation, the "Family

Caregiver Act”, which if passed will require live demonstration to caregivers as a form of training before discharge (Evans, 2016). Finally, Kentucky utilizes surveys through the waivers where a variety of information is collected relating to emotional wellbeing of those receiving HCBS (Wells, 2016).

Barriers

Finally, there were barriers uncovered relating to providing LTSS through home and community based settings. The table below depicts barriers brought up by the states. While there is not much overlap there is still significance in the results. Only three states were interviewed for the study but there are 51 states on the AARP scorecard. So, the barriers highlighted may affect the other states and their abilities to rebalance care. Additionally, Kentucky highlighted the most barriers, and they were the lowest performing, meanwhile, Oregon has the least barriers. This could represent that lower performing states are lower performing due to the barriers they face trying to rebalance care. Additionally, higher performing states like Oregon may be better able to rebalance their care because they face less issues in doing so. It is important to recognize that lower performing states, such as Kentucky may not be as well suited to rebalance LTSS due to barriers in creating new HCBS. There were not barriers per say discussed in New Jersey; this could likely be due to the limitation of only speaking to Nancy Day and utilizing supplemental information. While Day did not notice any barriers with programs it is naïve to assume there are not state barriers in providing HCBS and rebalancing care. Additionally, New Jersey did specify the need for nursing facilities and that the state will likely always fund institutional programs (Day, 2016).

Table 3 Barriers to Rebalancing

	Oregon	New Jersey	Kentucky
Entry for Becoming a Provider	x		
Pre-Enrollment Costs			x
Housing Availability			x
Legislation Process			x
Underutilization of Services			x
Necessity of Nursing Facilities		x	x
Funding	x		

The table shows Oregon has two barriers mentioned in interviews. The first is the issue of becoming a PACE provider (McCormick, 2016). The second issue Oregon faces is funding for training programs for informal caregivers (Bartholomew, 2016). However, Bartholomew mentioned the senior medical tax deduction plan has allowed for them to make up in lack of federal funding and utilize recovered money for training and other LTSS services (Bartholomew, 2016). Kentucky recognized several barriers in rebalancing care. The main issues determined include pre-enrollment costs, housing availability, legislation process, and underutilization of services and necessity of nursing facilities. Kentucky found the pre-enrollment costs for caregivers as an issue. Informal caregivers expressed concerns about the costs associated with the drug test and background checks the state requires in becoming an informal caregiver (Gresham, 2016). Furthermore, Kentucky lacks suitable homes or communities for residents to be transitioned to; this could be associated with the caregiver's barrier to paying pre-enrollment costs. Furthermore, Kentucky believes the legislation advocates more for institutional settings

and the length of processing an act to go against that norm is long (Evans, 2016). Finally, similarly to New Jersey, Kentucky does not see their funding shifting dramatically in favor of HCBS, so their necessity of nursing facilities and other institutional settings is evident and prevents the state from rebalancing care.

Chapter 7

Conclusion

The purpose of the study is to analyze three states through on their efforts of rebalancing long- term care from institutional to home and community based settings. All three states while falling into unique positions for rebalancing care shared similarities in barriers, funding patterns, and overall ideas. Each state expresses a desire to focus funding and programs on home and community based services rather than intuitional based. More specifically, all states understand people would rather age in their homes for as long as possible and state's wish to honor those wishes. The findings are significant because lower performing states, such as Kentucky, can hopefully try to implement programs found in higher performing states. In contrast, it is important to recognize the impact that federal regulations, legislative process length, and funding has on states attempting to rebalance care and implement more HCBS. Another element observed is the need to focus on informal caregivers. New Jersey reveals their push of state funded programs for informal caregivers that other states can hopefully recognize and possibly adopt.

Top performer, Oregon, explained the state's adopted 'mantra' by which they seek to provide residents with "independent, choice, and dignity" through providing HCBS (Bartholomew, 2016). By moving past the idea of simply offering HCBS, and striving to utilize it in multiple fashions offering it as the foundation for long- term care, Oregon has become a national leader in rebalancing care. Furthermore, Oregon explains programs that are unlike any other programs discussed, that are creative in diverting funds directly to the elderly population that are not from federal or state grants. New Jersey, the middle performer, has a main focus on

HCBS through federal programs such as their MFP, I Choose Home, and BIP. Kentucky, while the lowest performer of rebalancing care is not in the dark when it comes to HCBS.

Kentucky interviews revealed the state is aware of the citizen's preference to HCBS and agencies such as AARP and other community avocation groups are voicing their opinion for change. Kentucky focuses on HCBS mainly through their waiver programs, which interviewees had conflicting opinions of utilization levels. There is trouble for Kentucky that stems from state legislation; there is still a large lobby advocating for nursing homes. Furthermore, the expressed thoughts of underutilization of the MFP demonstration and other waiver programs are relevant. While the three states fall at different rankings for their rebalancing of long-term care, they have two main elements in common. The states recognize the importance of providing home and community based services along with, and even over, institutional based services; and the states understand there are always areas for improvement in providing home and community based services in order to provide cost effective care that is high in quality for their residents.

Appendix A

Interview Questions

Cost Effectiveness

1. How much money do you spend on institutional based care? How much do you spend on community based care?
2. Do you feel your state advocates more for institutional based care or community based care?
3. What do your trend lines for funding look like, are they consistent or shifting?

Transitioning

1. Money follows the person question (all states have this demonstration)
 - a. I have observed your state has a money follows the person demonstration, how did your state come about creating this program? What benefits have you noticed from this program? What were some of the decision factors considered in creating this program? Have you observed cost savings associated with transitioning residents from institutional to community-based services?
2. Balancing Incentive Program
 - a. All States
 - i. I have observed your state was eligible for and is approved to participate in the balancing incentive program, have you noticed beneficial spending shifts associated with your enrollment?
 - ii. What decisions led to your state implementing a balancing incentive program? Do you believe your state benefitted from enrolling in this program?
3. All Inclusive Care for the Elderly—PACE
 - a. New Jersey
 - i. I noticed your state has a PACE benefit covered by Medicaid to two groups the categorically needy and the medically needy, how did your state come to the decision to include coverage for this program? What benefits have you noticed from this program?
 - b. Oregon and Kentucky
 - i. I noticed your state does not have Medicaid coverage for a PACE program, have you considered implementing coverage for such an inclusive care program? If you have thought of covering this benefit what barriers have prevented your state from doing so?
4. What other programs does your state offer in terms of Home and Community-Based Long-Term Services and Supports that you believe are most beneficial
 - a. How did you decide which programs to implement over other possible programs?
 - b. What decisions went into implementing such programs?
 - c. How have you continued these programs?

1. After observing your AARP Long-Term Services and Supports Scorecard Results I have noticed you had 3rd highest rank overall. You ranked in the 2nd quartile for support for family caregivers.
 - a. What types of programs do you offer to these informal caregivers?
 - b. How did you come to the decisions of creating these training programs?
 - c. Did you face any barriers implementing these training programs?
 - d. Do have any plans to improve or expand upon these programs?

New Jersey

1. After observing your AARP Long-Term Services and Supports Scorecard Results I have noticed you rank in the middle or 26th overall and you ranked in the 2nd quartile for support for family caregivers.
 - a. What types of programs do you offer to these informal caregivers?
 - b. How did you come to the decisions of creating these training programs?
 - c. Did you face any barriers implementing these training programs?
 - d. Do have any plans to improve or expand upon these programs?

Kentucky

1. After observing your AARP Long-Term Services and Supports Scorecard Results I observed you are in the bottom quartile for support for family caregivers.
 - a. Has your state worked to implement support programs for informal caregivers?
 - b. Has your state faced any barriers in implementing programs for caregivers?
 - c. Do you have any current plans to implement or renew programs for caregivers?

Every State

1. Does your state offer patient direction programs?
 - a. If yes → What barriers did you face upon implementing such programs? What benefits do you observe with such a program?
 - b. If no → Does your state have any plans to implement such a program? Have you tried to implement such programs before, have there been any barriers preventing you from doing so?
2. Does your state have any specific programs targeted at observing the emotional wellbeing of elderly citizens in home and community based care settings or institutional settings?
 - a. If yes → which programs do you have? How did you come up with these programs?
 - b. If no → do you have any current plans to create such programs? Has your state observed any barriers in implementing these programs?

Appendix B

As mentioned in the background section there are seven waivers, the first is for those with an acquired brain injury, to qualify one must be over 18 years old with have an acquired brain injury meeting skilled nursing facility level of care who are expected to benefit from the waiver services (DMS, 2017b). The second waiver is also for those with an acquired brain injury however are expected to need the services for life and have reached a plateau in their rehabilitation, unlike the first waiver where eligible citizens are expected to hopefully return to the community (DMS, 2017c). The next waiver is a Home and Community Based Waiver, which is a general waiver for adults and children who are financially eligible and meet a nursing facility level of care who wish to remain in their home for services (DMS, 2017d). Similarly, the Home Health waiver is for those of all ages, Medicaid eligible, whose services are hopefully short term and the services, must be prescribed by a physician (DMS, 2017e). The Michelle P. Waiver is for those with an intellectual or developmental disorder who require a protected area to learn everyday living skills and educational elements. The Model II Waiver is strictly for those requiring a ventilator for 12 or more hours a day meeting intense hospital- based nursing care daily (DMS, 2017f). The final waiver is the Supports for Community Living Waiver which is a general waiver for those with intellectual and developmental disabilities who meet requirements to live in an intermediate care facility but would prefer to receive services in their home (DMS, 2017g). The other element of Kentucky's LTSS are nursing facility services. Kentucky citizens are eligible for nursing facility services (DMS, 2017h).}

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