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Stakeholder Feedback on Implementation of the Managed Care Expansion in Long-Term Services and Supports (Round 3)

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Executive Summary

In July 2014, New Jersey brought four §1915(c) home and community based services (HCBS) waivers into managed care with its comprehensive §1115 demonstration waiver, creating the program in managed long-term services and supports (MLTSS). As of July, 2019, the state reported that 54% of the Medicaid long-term care population was in HCBS, up from about 29% in July of 2014.

This report is part of Rutgers Center for State Health Policy's evaluation of the renewal demonstration waiver, and is designed to describe the viewpoints of stakeholders regarding managed long-term services and supports (MLTSS). It is the third in a series of reports based on interviews with a variety of stakeholders as well as review of program-related documents and observation of meetings relating to MLTSS (see also Farnham, Chakravarty & Lloyd 2017; Farnham, Chakravarty & Lloyd 2015).

This report includes 18 interviews with 26 key informants conducted from April through June 2020. A total of 89 individuals participated in either individual or group interviews between the three rounds of interviews. In addition, five state subject matter experts provided written comments on an initial draft of this report in July 2020. Our 2017 report included 27 interviews with 69 individuals (Farnham, Chakravarty & Lloyd 2017), while our 2015 report included 16 interviews with 34 individuals (Farnham, Chakravarty & Lloyd 2015).

Interviewees included representatives of state agencies involved in MLTSS implementation, managed care organizations participating in MLTSS, advocacy groups for older adults and younger people with disabilities, providers of LTSS, and agencies or associations of agencies that work with MLTSS enrollees in a variety of contexts and in some cases provided case management services under the former §1915(c) waivers (e.g., county welfare agencies, Area Agencies on Aging, Centers for Independent Living, and Special Child Health Case Management).

Our interview responses fell into four broad themes: 1) The effects of MLTSS on enrollment, care management, and access to services; 2) communication among stakeholders and state regulation of MCOs; 3) reflections on LTSS design; and 4) the broader LTSS environment.

Theme 1: Effects of MLTSS on Enrollment, Care Management, and Access to Services

Enrollment

- HCBS enrollment nearly tripled in the 5 years following the inception of MLTSS, with the number enrolled in HCBS increasing from less than half the population residing in nursing homes in July 2014 to exceeding the nursing home population as of late 2018.
- Stakeholders generally think that having a unified MLTSS program makes it easier to learn about available services and the standardized menu of services avoids the need to make difficult choices between competing programs for consumers.
- The state has taken steps to ensure that only people with recent eligibility are enrolled.
- Longstanding system issues (discussed in theme 4) continue to complicate and in some cases delay enrollment, particularly for consumers who are first enrolling into Medicaid because of a need for LTSS.

Care Management

MLTSS represented a shift in the design of care management, bringing it into MCOs instead of a variety of county and private (both nonprofit and for-profit) agencies. When thinking about how care management has changed with MLTSS, it is important to keep in mind that limited comparative information exists on processes and outcomes in pre/post MLTSS periods, that MLTSS is implemented somewhat differently in each of 5 MCOs, and that MLTSS may have different effects on different groups of consumers.

Interviewees were divided as to their opinions on whether the effects of MLTSS on care management were positive or detrimental, and sometimes the same interviewee saw positive effects for some consumers and negative effects for others. Interviewee comments and a federal audit report (Grimm 2020) make clear that there is room to improve MLTSS care management going forward. However, it is often not possible to tell the extent to which current concerns compare with the prior system.

Perceived benefits of MCO care management under MLTSS included better coordination with more involvement of the care manager in different types of care, addition of housing navigators to managed care, and MCO assistance with transitions from nursing home to community settings.

Concerns about MCO care management under MLTSS included perceptions of declining quality of care management for more complex individuals, overwhelmed care managers, turnover at all levels of the MCOs, perceived lack of consumer access to their MCO care plans, lack of visibility of care managers in nursing homes (not a role of pre-MLTSS case managers), perceived lack of familiarity of care managers with mental health issues (not a responsibility of pre-MLTSS case managers), and lower required levels of care manager contact with enrollees.

Access to Services

By far the largest concern about access to services expressed among interviewees was lack of access to or reduction of hours in private duty nursing (PDN) or personal care assistance (PCA), particularly for consumers with higher needs. Concerns covered:

- the inadequacy of assessments of needed hours,
- lack of availability of workforce to staff the hours,
- reductions in hours by MCOs, and
- problems with the notification and appeals processes regarding reductions in service.

MCOs expressed dissatisfaction with the assessment and appeals processes, though their perspective was very different from other stakeholders.

Other access concerns included:

- Time needed for approval of caregivers under the Personal Preference Program (i.e., self-direction).
- Gaps in some services, particularly social adult day services, non-medical transportation (particularly in more sparsely populated areas), and direct care workers (including nurses to provide PDN as well as aides to provide home care assistance).
- Home-delivered hot meals (as opposed to bulk home delivered meals).
- Access to rehabilitative services for consumers with traumatic brain injury.
- Redundant authorizations required for ongoing care.

Theme 2: Communication Among Stakeholders and State Regulation of MCOs

MCO interviewees reported the highest level of satisfaction with their relationship with state officials, with providers somewhat behind and consumer advocates considerably further behind.. The state has to meet more frequently with MCOs because they are charged with regulating them. Until March of 2019 there was an MLTSS Steering Committee that met quarterly. Consumer advocates seemed to feel the most urgency for reinstating that, feeling that other methods of communication such as the quarterly Medical Assistance Advisory Council (MAAC) meetings for all Medicaid-related programs, were not adequate.

There are state hotlines for provider and member quality issues, which interviewees thought were responsive, but underresourced. Consumer advocates would like the quality hotline to be better publicized.

MCO Contracts require advisory committees and MLTSS member representatives, and some stakeholders meet among themselves to discuss issues.

Overall, as in our previous reports, providers and consumers still feel that the state is too deferential toward the MCOs, though a Fall 2019 action to freeze enrollment in one MCO was noted, and regulatory actions may not always be made public. Interviewees also wanted to see more transparency with respect to quality reporting (including details on spending breakouts) and individual budgets, so that advocates could verify cases where MCOs said that people's services were higher than necessary and warranted reductions.¹

Theme 3: Reflections on LTSS Design

Some interviewees still question the desirability of a managed care model for MLTSS, pointing to a potential ASO (administrative services organization) model that would not have any incentive to minimize services. There are also questions about the inclusion of nursing home care in MLTSS, with some stakeholders thinking it should be removed, and others nervous that this would incentivize MCOs pushing expensive consumers toward nursing homes to get the highest cost individuals off their books. One interviewee argued for a different level of care requirement for consumers getting HCBS to better prevent institutionalization.

Theme 4: Broader LTSS Environment

There are a number of issues in the broader LTSS environment that affect MLTSS-related organizations and members that were raised in our interviews, including:

- 1) Nationwide shortages of direct care workers and nurses
- 2) Problematic linkages/gaps in communication that complicate Medicaid enrollment and redetermination
- 3) Gaps/lack of role clarity in the social safety net which in some cases have been complicated with the addition of MCOs

¹ MCO contract section 9.3.2 requires an individual cost effectiveness analysis and specific notification requirements of any adverse action taken, and discussions are required when a threshold is approached. The analysis is part of the care management record detailed in 9.2.2B and part of the care plan detailed in 9.6.4K that is required to be shared with the member.

- 4) Remaining silos between programs that prevent consumers from getting the best possible services

To some degree, perceptions vary by stakeholder role. Providers feel negatively impacted in several ways—rate decreases, payment delays, the need to obtain authorization for services, and the increased administrative burden of working with 5 MCOs instead of one single state payer. Providers and advocates sometimes feel that state staff don't include them enough in system discussions, or that state staff defer to MCOs on matters where they feel the state should take a more active role.

Advocates encounter people who are having problems with MLTSS and detailed many issues with still-fragmented systems, service reductions and gaps, lack of proper care management, lack of data-sharing and transparency, and to some degree the lack of advocate involvement in stakeholder and policy discussions.

MCOs reported being generally satisfied with their relationships with the state and others. Together with advocates, they think that the fair hearing process is too lengthy. One would like faster turnaround on the results of quality initiative audits to allow them to address any problems in a more timely way.

State staff remain determined to make the program work with the resources they have available and remain committed to a philosophy of continual improvement. Advocates and providers generally seem to feel that problems that they identify to state staff are addressed and usually resolved, but in many cases feel that there was too much effort expended on their part or that they had to know who specifically to contact in a way that the average consumer, particularly the vulnerable populations that tend to be receiving MLTSS, would not be able to.

All stakeholders feel that data that might provide answers to some advocates' concerns about how quickly people are able to access services, gaps in services, and participants' well-being have been slower in coming than is desirable. The state continues to work to address such questions. Experts have noted the difficulty of measuring quality in LTSS, so New Jersey is not unique in experiencing this issue (Thomas and Appelbaum 2015).

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Introduction

Background

In July 2014, New Jersey brought four §1915(c) home and community based services (HCBS) waivers into managed care with its comprehensive §1115 demonstration waiver. Many states are bringing long-term services and supports (LTSS) into the range of services managed by managed care organizations (MCOs). Services organized in this way are often referred to as managed long-term services and supports, or MLTSS. MLTSS involves capitated payments (i.e., a standardized payment per enrollee) to the MCO for long-term services and supports. Enrollees may be separated into different categories based on clinical need (often called acuity) and setting (community, facility, etc.), with different payment amounts for different categories. Long-term services and supports (LTSS) refers to assistance with activities of daily living (ADLs), such as bathing, eating, dressing, and using the toilet and instrumental activities of daily living (IADLs), such as shopping, preparing meals and managing medications. Collectively, ADLs and IADLs represent those activities that are generally necessary for independent living. LTSS may be delivered in an institutional setting, such as a nursing facility, or in a community setting, such as a private home. MCOs are required to offer a standard package of services to enrollees² and meet other requirements,³ such as having an adequate network of providers, but each MCO may contract with a different group of providers, so the LTSS experience of enrollees may differ across MCOs, and even within an MCO, based on the particular providers the patient is using or the MCO staff with whom the enrollee interacts.

Rutgers Center for State Health Policy (CSHP) was contracted by the New Jersey Department of Human Services to evaluate the demonstration. CSHP has published several reports that relate at least in part to the managed care expansion into LTSS services: two regarding stakeholder

² See the MLTSS Services Dictionary at http://www.nj.gov/humanservices/dmahs/home/MLTSS_Service_Dictionary.pdf (accessed June 1, 2020).

³ See the contract between managed care organizations and the state at <http://www.state.nj.us/humanservices/dmahs/info/resources/care/hmo-contract.pdf> (accessed June 1, 2020).

feedback on MLTSS (Farnham, Chakravarty & Lloyd 2017; Farnham, Chakravarty & Lloyd 2015), and two waiver evaluation reports analyzing the effect of the waiver on access to care, quality, and costs of care (Chakravarty et al. 2017; Chakravarty et al. 2016).

Purpose of this Report

The Waiver Special Terms and Conditions requires an evaluation plan that enumerates specific research questions.⁴ This report will discuss our third round of collection of stakeholder feedback (the first two rounds were for the base waiver, while the third round is for the renewal) on the implementation of the managed care expansion into LTSS, and partially addresses Questions 1 through 4 on aspects of the managed care expansion, and the portion of Question 11 relating to stakeholder perspectives on managed care:

- Q1. What is the impact of the managed care expansion on access to care, the quality, efficiency, and coordination of care, and the cost of care?
- Q2. What is the impact of including long-term care services in the capitated managed care benefit on access to care, quality of care, and mix of care settings employed?
- Q3. What is the impact of the hypothetical spend-down provision on the Medicaid eligibility and enrollment process? What economies or efficiencies were achieved, and if so, what were they? Was there a change in the number of individuals or on the mix of individuals qualifying for Medicaid due to this provision?
- Q4. What is the impact of using self-attestation on the transfer of assets look-back period of long term care and home and community based services for individuals who are at or below 100 percent of the FPL. Was there a change in the number of individuals or on the mix of individuals qualifying for Medicaid due to this provision?
- Q11. What do key stakeholders (covered individuals and families, advocacy groups, providers, health plans) perceive to be the strengths and weaknesses, successes and challenges of the expanded managed care program, and of the DSRIP pool? What changes would these stakeholders recommend to improve program operations and outcomes?

The goal of the report is to show readers what the implementation has looked like from different stakeholder perspectives, discussing where perspectives are similar and where they may diverge. In many cases we cannot adjudicate differences in perspectives to ascertain if there is one correct view. Where possible, we draw upon relevant data to examine the extent to which stakeholder experiences may be generalizable. To the extent that judgments are made about competing perspectives, our highest priority interest is the health and quality of life of consumers enrolled

⁴See the evaluation plan at https://www.state.nj.us/humanservices/dmahs/home/1115_Demonstration_Special_Terms_Conditions_Attachment_M_Evaluation_Design.pdf (accessed June 1, 2020).

in MLTSS, and the population health among people in New Jersey who are or may become eligible for MLTSS, whether enrolled or not. Some discussion of operational details and programmatic changes that have occurred is included to give context to the findings, along with material on the national picture in MLTSS.

Target readers include stakeholders in New Jersey, CMS staff, and stakeholders in other states who are implementing, managing, or considering MLTSS programs.

It was apparent to us in attending meetings and conducting interviews that stakeholders are very committed to fostering positive relationships with other stakeholders and working constructively together to implement and to improve MLTSS as it moves forward. It is our hope that this report will fit into this framework of constructive relationships.

New Jersey and the National Picture

States have increasingly adopted MLTSS over time (Dobson et al. 2017, Lewis et al. 2018, MACPAC 2018, Gifford et al. 2019). Gifford et al. (2019) note that Alabama and Washington state have managed fee-for-service LTSS models. Washington had one MLTSS program in the past, but has moved to a different approach. Most Medicaid MLTSS waivers have been approved fairly recently—the first was approved in 1989, the second in 1998, five from 2000-2010 and the rest later. Nearly all the waivers include older adults and younger people with physical disabilities (as New Jersey’s program does). New Jersey’s waiver designed for people with intellectual and developmental disabilities⁵ remains outside MLTSS. Most waivers are statewide and require enrollment in managed care, as New Jersey’s program does. All waivers include home and community based services (HCBS). A small number of states do not include behavioral health or acute/primary care. New Jersey’s waiver includes these services. Many states have some kind of carve-out for institutional care (Lewis et al. 2018). New Jersey includes institutional care benefits for new enrollees or those who have changed levels of care, but New Jersey consumers who were in a nursing facility at the time of MLTSS implementation remain fee-for-service unless they change facility or level of care. In January 2016, New Jersey’s dual eligible special need plans (D-SNP) for consumers eligible for both Medicare and Medicaid became fully integrated, meaning that they cover both acute and long-term services (Ensslin & Kruse 2016; Verdier et al. 2015).

National research has raised concerns about the limited experience of MCOs in managing LTSS, the administrative capacity of LTSS providers to operate within a managed care system, and state capacity in terms of the number and expertise of personnel to oversee MLTSS (Burwell and

⁵ The Community Care Program — see <http://www.state.nj.us/humanservices/ddd/services/ccw/> (accessed June 26, 2020).

Kasten 2013, Lipson et al. 2012). A recent New Jersey report noted dwindling staffing among many state agencies (Reynertson & McCoy 2020).

In October of 2016, the National Quality Forum endorsed the Home and Community-Based Services Consumer Assessment of Healthcare Providers and Systems (HCBS CAHPS) Survey.⁶ CMS has documented a lot of activity in MLTSS measure development.⁷ New Jersey was among the earliest states to participate in the National Core Indicators—Aging and Disabilities (NCI-AD) Adult Consumer Survey beginning in 2015-2016.⁸ MLTSS is one of the programs evaluated in the survey. New Jersey Medicaid’s Quality Strategy outlines 40 quality metrics for MLTSS (DMAHS 2014), and waiver renewal documents released in 2017 summarize the state’s quality and monitoring activities.⁹

MLTSS in New Jersey

MLTSS in New Jersey is provided through a comprehensive §1115 waiver that combined several §1915(c) waivers serving people who have care needs at an institutional level along with new entrants to nursing facilities. Residents of nursing facilities at the time of MLTSS implementation remain in a fee-for-service arrangement unless they have a change in the status of their level of care. The largest prior §1915(c) waiver, Global Options (GO), had served older adults and transitioned 10,949 consumers into MLTSS. Three smaller waivers included or targeted younger individuals. The Traumatic Brain Injury (TBI) waiver included people diagnosed with acquired brain injury after age 21 but before age 65, and transitioned 309 consumers into MLTSS. Community Resources for People with Disabilities (CRPD) served individuals of any age, including children, and transitioned 330 consumers into MLTSS. The AIDS Community Care Alternatives Program (ACCAP) waiver served individuals of any age with AIDS and children under the age of 13 who were HIV positive, and transitioned 154 consumers into MLTSS.

Table 1: Former Waiver Members Transitioned to MLTSS

Former Waiver	Number Transitioned to MLTSS	Percent of Total
GO (older adults)	10,949	93.2%

⁶ For the endorsement, see <http://www.qualityforum.org/Qps/MeasureDetails.aspx?standardID=2967&print=0&entityTypeID=1> ; for the surveys, see <https://www.medicaid.gov/medicaid/quality-of-care/performance-measurement/cahps-hcbs-survey/index.html> (accessed April 12, 2017).

⁷ See <https://www.medicaid.gov/medicaid/managed-care/managed-long-term-services-and-supports/index.html> (accessed June 26, 2020).

⁸ See reports and other information at <http://nci-ad.org/resources/reports/> (accessed June 26, 2020).

⁹ See http://www.nj.gov/humanservices/dmahs/home/NJCW_Renewal_App_B_Quality_Activities.pdf , part of the January renewal application, or Attachment B from the February application, available at <https://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Waivers/1115/downloads/nj/nj-1115-request-pa3.pdf> (accessed April 12, 2017).

TBI	309	2.6%
CRPD	330	2.8%
ACCAP	154	1.3%
<i>Total</i>	11,704	100%

Source: NJ Department of Human Services, Quality Committee, March 2015

As of July, 2019, the state reported that 54% of the Medicaid long-term care population was in HCBS, up from about 29% in July of 2014. The nursing facility population (comprising fee-for-service and MLTSS) decreased by nearly 2,000 individuals between July 2014 and July of 2019. Of the June 2014 HCBS waiver population, only 8% were in nursing homes as of October 2019, a percentage that has remained similar across our reports on this topic.¹⁰ This indicates that MLTSS has been successful in keeping people in HCBS settings.

COVID-19 Pandemic Effect on NJ

New Jersey has seen the second-highest number of fatalities in the COVID-19 pandemic as of June 2020 (behind New York), and consumers enrolled in MLTSS are at high risk. New Jersey's hospitalizations peaked on April 14, 2020 at 8,065. As of June 23, 2020, New Jersey had 12,949 deaths from the pandemic, 6,422 (50%) of whom were residents of long-term care facilities and another 117 who were staff. Of the 169,734 cases as of June 23, 2020, 23,823 are long-term care residents and 12,177 are facility staff (residents and staff together comprise about 21% of total cases). Eighty percent of deaths of COVID-19 patients have been in residents ages 65 and over, and underlying conditions such as heart disease, diabetes, and other chronic conditions are frequent among COVID-19 decedents.¹¹ An executive directive requiring testing of nursing home staff and residents was issued May 12, 2020, to be implemented by May 26.¹² A report was issued in early June, 2020 regarding recommendations for New Jersey nursing homes (Manatt 2020).

The pandemic started to affect the state noticeably in March 2020, before we began our interview recruiting. We had more difficulty recruiting than in prior rounds, but felt we got an adequate response to meet our report due date.

MCOs indicated that they had moved to telephonic care management during the pandemic. New Jersey Medicaid outlined a variety of steps taken to address the pandemic.¹³

¹⁰ From https://www.state.nj.us/humanservices/dmahs/boards/maac/MAAC_Meeting_Presentations_10-24-19.pdf (accessed June 25, 2020).

¹¹ All data cited are from the NJ Department of Health: https://www.nj.gov/health/cd/topics/covid2019_dashboard.shtml (accessed June 23, 2020).

¹² Accessed June 26, 2020 from <https://www.nj.gov/governor/news/news/562020/20200512c.shtml>

¹³ See agenda, presentations and audio for April 22, 2020 at <https://www.state.nj.us/humanservices/dmahs/boards/maac/> (accessed June 25, 2020).

Methods

The primary method of collecting information regarding stakeholder feedback was through key informant interviews. However, the evaluation team also attended a variety of meetings with stakeholders to gather background information, and noted media or other secondary sources where relevant to our inquiry.

Interview Subject Recruitment

The research protocol was approved by the Institutional Review Board at Rutgers. Eighteen interviews (17 by telephone and one via email) with 26 key informants were conducted from April through June 2020. Phone interview duration ranged from 40 minutes to 2 hours, with an average of about 80 minutes. Subjects were recruited by CSHP or suggested by other interviewees. There were about 6 groups we were hoping to interview who either didn't respond or were unable to find time for an interview. We had fewer providers and state participants than in past rounds, but we believe the results are still useful. Fifteen of the 26 individuals had been interviewed in one or both of the previous rounds (Farnham, Chakravarty & Lloyd 2017; Farnham, Chakravarty & Lloyd 2015). The true overlap is probably greater than the numbers would suggest because in some cases, similar people were interviewed when people changed organizational positions, or similar types of organizations (e.g., providers) were included. A total of 89 individuals have participated in either individual or group interviews among the three rounds of interviews. Interviews from previous rounds are considered as background information for this analysis. Five state subject matter experts provided written comments on an initial draft of this report in July 2020. They are not included in the interviewee count for this report, since their interaction with us was more limited, but some of them had participated in past interviews and are included among the 89 individuals mentioned.

Interviewees included a variety of stakeholders, including advocacy groups for older adults and younger people with disabilities, LTSS provider associations, and agencies or associations of agencies that work with MLTSS enrollees in a number of contexts. In some cases these agencies had provided case management services under the former §1915(c) waivers (e.g., county welfare agencies, Area Agencies on Aging, and Special Child Health Case Management). In some cases interviews included multiple individuals. Table 2 shows a breakdown of the number of interviews and interviewees by organization type. The largest share of interviewees were from nonprofit organizations who served consumers or advocated on their behalf, and the next largest share were county or state agency staff (or county/state subcontractors) who interact with or work for the benefit of MLTSS consumers. Provider associations and MCOs rounded out the interviews.

To protect the confidentiality of our interviewees, we are not listing the names or specific organizations of those with whom we spoke.

Table 2: Round 3 Interviewee Breakdown by Type of Organization

Type of interviewee	Interviews	% Total	Individuals	% Total	Repeat interviewees	% Total
Consumer/Advocacy organizations	7	39%	10	38%	7	47%
Provider associations	3	17%	4	15%	3	20%
County/state agencies or contractors	5	28%	8	31%	3	20%
MCOs	3	17%	4	15%	2	13%
<i>Total</i>	18	100%	26	100%	15	100%

Question Development

Questions were developed to address the research questions detailed in the Waiver Special Terms and Conditions¹⁴ regarding the impact of MLTSS on access to care and the quality of care received, the impact of procedural changes in the eligibility process and the perceptions of stakeholders regarding the program. Informing the questions was knowledge gained by CSHP researchers through observation and/or participation in various meetings, conference calls, and review of various reports and news articles regarding MLTSS. We attempted to keep the questions similar to those asked in previous rounds to facilitate comparisons over time. As the interviews progressed, information from earlier interviews was used to create new follow-up prompts for later interviews.

Questioning Strategy

All interviews were conducted by a senior research analyst with a background in long-term services and supports research and evaluation. The interviewer used a semi-structured list of basic questions noted in advance and also created new follow-up questions at the time of the interview if appropriate (See Appendix A for the list of questions). Interviewees were given a handout containing the basic questions prior to the interview along with consent information for the study.

¹⁴ See pp.99-101, Centers for Medicare & Medicaid Services, Special Terms and Conditions (STCs), Number 11-W-00279/2, New Jersey Comprehensive Waiver Demonstration, New Jersey Department Human Services Division of Medical Assistance and Health Services, October 1, 2012 through June 30, 2017. Accessed June 18, 2015 from http://www.state.nj.us/humanservices/dmahs/home/CMW_STCs.pdf.

Documentation and Analysis

Interviews were audio-recorded if all participants were willing to allow recording.¹⁵ Themes were identified using an inductive process (Thomas 2006). Because interviewees are in some cases unique, but are also selected on the basis of having contact with multiple stakeholders, there are times when we include something said by only one interviewee. We note when this is the case. Interviews from previous rounds are considered as background information for this analysis (Farnham, Chakravarty & Lloyd 2017; Farnham, Chakravarty & Lloyd 2015).

Findings

We found that our interview responses fell into four broad themes: 1) The effects of MLTSS on enrollment, care management, and access to services; 2) communication among stakeholders and state regulation of MCOs; 3) reflections on LTSS design; and 4) the broader LTSS environment.

Theme 1: Effects of MLTSS on Enrollment, Care Management, and Access to Services

1.1 Enrollment

Trends. HCBS enrollment nearly tripled in the 5 years following the inception of MLTSS, as shown in Table 3, with the number enrolled in HCBS increasing from less than half the population residing in nursing homes in July 2014 to exceeding nursing home population as of late 2018. The nursing home population is down slightly over the 5 year period and PACE¹⁶ (which can be HCBS or nursing home) is up nearly 40%. As noted in earlier reports, stakeholders generally think that having one MLTSS program rather than several waivers makes it easier to learn about available services and the standardized menu of services avoids the need to make difficult choices between programs for consumers.

¹⁵ Three of the 18 were not recorded. Two didn't feel they were situated to do a full interview (though we felt their participation counted as an interview). They gave useful comments and in one case compiled information from others with more direct experiences. One was a group interview where one person was not comfortable with recording.

¹⁶ See <https://www.state.nj.us/humanservices/doas/services/pace/> for more information on PACE (accessed June 25, 2020).

Table 3: New Jersey Long-Term Care Population by Setting

Setting	July 2014	July 2019	Percent Change
Nursing Home	29,304	27,312	-6.8%
HCBS/AL	11,401	31,266	174.2%
PACE	828	1,147	38.5%

Source: MAAC Presentation October 24, 2019, slide 22¹⁷

Processes. In order to be eligible for MLTSS, consumers must be both financially eligible for Medicaid and meet clinical eligibility standards, which require a nursing facility level of care.¹⁸ Financial eligibility is determined by county welfare agencies prior to enrollment into Medicaid.¹⁹ Clinical eligibility is determined directly by or with oversight from the Office of Community Choice Options (OCCO),²⁰ under the Department of Human Services, Division of Aging Services. For consumers already enrolled in a Medicaid MCO, the MCO completes the clinical eligibility determination and uploads it for OCCO approval. For consumers new to Medicaid, OCCO completes the clinical eligibility determination. A state auditor’s report (Eells 2018) noted that a state system set in place to automatically enroll beneficiaries with the requisite clinical and financial eligibility into MLTSS was allowing outdated clinical assessments.²¹ The state noted in its response that it had changed the system parameters and tightened contract requirements on MCOs to make timely clinical assessments.

MCOs generally reported satisfaction with the enrollment process, including switches between MCOs (the state has facilitated some information transfer for those cases). However, one MCO noted a problem with consumers who are dropped from Medicaid after not submitting their financial redetermination paperwork. When reenrolled, the member may not recall the name of

¹⁷ Accessed June 25, 2020 from

https://www.state.nj.us/humanservices/dmahs/boards/maac/MAAC_Meeting_Presentations_10-24-19.pdf

¹⁸ See Hogan (2014) for a discussion of the assessment process. Consumers meet nursing facility level of care if they require at least limited assistance (physical guidance without taking weight) with at least three ADLs (eating, bathing, dressing, transfer/toilet use, bed mobility, transfers and locomotion) or cognitive disabilities resulting in problems with memory, decision-making or communication coupled with a need for supervision in at least three ADLs). The most dependent episodes over the past three days are considered.

¹⁹ See “County Welfare Agencies (Boards of Social Services)”

<http://www.state.nj.us/humanservices/dfd/programs/njsnap/cwa/> (accessed June 22, 2020).

²⁰ OCCO approves all clinical eligibility, including requests submitted by Medicaid MCOs. For individuals not yet on Medicaid, OCCO staff perform an in-person assessment. See “Office of Community Choice Options” <http://www.state.nj.us/humanservices/doas/home/directory.html> (accessed June 22, 2020).

²¹ For example, a non-MLTSS Medicaid enrollee might have a hospitalization with a discharge to a nursing facility and have a clinical eligibility put into the system via that pathway—see

<https://www.state.nj.us/humanservices/doas/services/pas/> and

<https://www.state.nj.us/humanservices/doas/documents/1.1%20Hospital%20EARC%20Certification%20and%20EARC%20Portal%20Overview.pdf> for an explanation of clinical eligibility pathways (accessed June 30, 2020).

their prior MCO in order to select it, and may be autoassigned to a different MCO, which is not ideal for care continuity. This interviewee thought that there should be a better warning system for members in need of redetermination so that MCOs could facilitate outreach to them, and that members who are dropped and reenrolled should be reassigned to the same MCO they had before. The state notes that if a member is disenrolled from Medicaid and re-enrolls within 60 days, the member is automatically re-enrolled to the MCO they were in previously. If the member re-enrolls with Medicaid after 60 days of termination, then the member has to take action to ensure they are enrolled into the same MCO. The MCO can request the member be re-enrolled with them.

There have been longstanding issues prior to MLTSS implementation and continuing beyond with delays in the process of eligibility determination, which will be discussed in Theme 4. These issues continue to complicate and in some cases delay enrollment, particularly for consumers who are first enrolling into Medicaid because of a need for LTSS. Qualified income trusts, which replaced the medically needy designation and allow higher income consumers to receive services in community settings,²² are still seen as confusing by many stakeholders, but the access they grant is seen as a positive.

1.2 Care Management

Design of care management function. Prior to MLTSS, waiver case management was provided by a variety of county and private (both nonprofit and for-profit) agencies, including Area Agencies on Aging, County Welfare Agencies, Centers for Independent Living, Special Child Health Services Case Management Units, and private nursing or service agencies. In some cases, these staff moved to MCOs; in other cases, they stayed with their organization with a changed role. With MLTSS, care managers are employed directly by MCOs. There is no contracting out of care management to community-based organizations.²³

Issues in comparing pre-MLTSS waiver case management to MCO-based care management under MLTSS. There are several important factors to keep in mind when thinking about the evaluation of care management in MLTSS based on our three rounds of interviews and our review of evaluation-related documentation:

- Limited comparative information exists on processes and outcomes in pre/post MLTSS.
- MLTSS is implemented somewhat differently in each of 5 MCOs.

²² See <https://www.state.nj.us/humanservices/dmahs/clients/mtrusts.html> (accessed June 26, 2020).

²³ At the beginning of MLTSS, one MCO did contract out care management to a Visiting Nurse Association for a short time, but they decided quickly to bring care management solely in-house. A state reviewer of this report noted that the MCO contract does not prohibit delegation of care management, although it does prohibit delegation of the NJ Choice Assessment.

- MLTSS may have different effects on different groups of consumers.

Perceived care management benefits and concerns under MLTSS. Interviewees were divided as to their opinions on whether the effects of MLTSS on care management were positive or detrimental, and sometimes the same interviewee saw positive effects for some consumers and negative effects for others. Interviewee comments and a federal audit report (Grimm 2020) make clear that there is room to improve MLTSS care management going forward. However, it is often not possible to tell the extent to which current concerns compare with the prior system. Where interviewees could compare, we have noted the difference, but in other cases we just present the current issue. Please note that the sections below may include the same issue as both a benefit and concern, as expressed by different interviewees.

Perceived MCO care management benefits noted by interviewees:

- Better coordination of services and care with one menu of services for all consumers and MCO coordination through transitions to hospital/rehab/home.
- Improvements in care manager contact, engagement, and continuity for older adult clients relative to the previous §1915(c) waiver were noted by one interviewee this round and two last round. The interviewee this time noted that for members with straightforward needs, MCOs could easily cover cases with different staff when needed without losing continuity of care (this interviewee saw a degradation in care for more complex members under MLTSS).
- Praise for addition of housing navigators to managed care (navigators are not just for MLTSS clients, but provide support to care managers).
- MCO care manager assistance with transitions from nursing homes to community settings. One interviewee noted that some MCOs have an experienced central staff who handle transitions, which they felt worked better than using each individual care manager, because they faced a learning curve.
- One interviewee felt that MCO care manager presence in nursing homes had improved since the last report (they also felt MCO care management was not particularly influential regarding nursing home quality of care, however).

An example from an interview that mentioned many of these items: *“what’s great about this new system is it’s really an overall pulling together of all of these services ... home care, and meals, whereas the old system, things were very ... siloed ... just meals, they’re not going to help you with housing ... more of a unified approach, which is obviously helpful for the individual. The other thing I have been impressed ... positive development ... when [organization] clients are admitted to the hospital, for rehab, and then they return home, having the MCO involved throughout that*

whole transition has been very helpful ... MCO contact has been pivotal in that transition, it's been really good to just have something consistent for the client."

Perceived MCO care management concerns noted by interviewees:

- Degradation of care management for complex consumers (who tended to be younger) due to lower care manager expertise or engagement, care manager turnover, and/or service reductions.
- Overwhelmed care managers who are not able to do holistic assessments or management. A federal audit report of 2016 cases (Grimm 2020) noted shortcomings in MLTSS care management.²⁴ One interviewee, though they noted some difference in this across MCOs, thought ratios needed to be decreased across the board to allow for better care management. In both our second and third rounds of interviews, we heard reports of (but did not speak directly with) care managers who had departed MCOs feeling like they were assigned too many clients and, in some cases, felt they were being incentivized to reduce services (another interviewee in the second round perceived that most care managers they dealt with were satisfied).²⁵
- Turnover at all levels at MCOs, negatively impacting the ability of stakeholders to communicate with MCOs about operational issues, including care management. Several interviewees mentioned this, and they perceived the turnover as greater than had existed in the previous system, and not just due to enrollment growth, which necessitates adding staff.
- Several interviewees in this and previous rounds noted problems for consumers in accessing a copy of their care plan (either by the consumer or by advocates who were trying to help them). MCOs we interviewed said that the plan was provided either immediately at the discussion or mailed shortly afterward.
- Lack of presence/visibility of MCO care managers in nursing homes. Nursing home residents had not had care managers under the previous fee-for-service system (perceived benefits of their presence for transitions is noted above). Care managers can have up to 240 nursing home resident members, much higher than for other categories,²⁶

²⁴ The focus of this report (Grimm 2020) was very acute care oriented compared to the existing MLTSS Quality Measures and the kinds of comments our interviewees made, which generally concerned LTSS. The record review was by a physician looking at MCO records (i.e., consumers were not contacted). The report did not comment on the adequacy of the existing state evaluation framework for MLTSS, which does not emphasize the kinds of acute care service coordination examined by the CMS physician. It also was not clear to us whether there were duration of enrollment requirements for records audited, which could affect the quality of care management observed.

²⁵ State staff did not report hearing this concern, and the MCO contract prohibits offering any incentive for reduction of services or any adverse determination (Section 4.6.4 (A)(7)), Contract Amended 1/2020, accessed from <https://www.nj.gov/humanservices/dmahs/info/resources/care/hmo-contract.pdf>

²⁶ See MCO Contract, Article 9, p.27: 1:240 for nursing homes; 1:120 for alternative community settings (such as assisted living); 1:60 for home and community based services; and 1:48 for pediatric special care facility. Available

which was a source of dissatisfaction for MCO interviewees, who felt they could do a better job if the state were to require lower ratios. Other interviewees felt that MCOs weren't adding value now in nursing homes and that there was no reason to increase their presence because the facility is responsible for managing care. This will be discussed further in Theme 3.

- Lack of familiarity by care managers with mental health issues, particularly as they relate to assessments of eligibility for MLTSS (case managers in the pre-MLTSS system would not have had this responsibility).
- Lower levels of required care manager contact with enrollees (the past system required at least monthly telephone contact, plus quarterly face to face, while the current system requires quarterly face to face). However, interviewees have noted that this requirement was not always met in the prior system, and one MCO reported that they require their care managers to do a minimum monthly check-in with enrollees, even though the contract does not require this.

1.3 Access to Services

The increased enrollment noted above leads to better access to services for those enrollees. In addition, the location of care managers in MCOs gives them the opportunity to coordinate care among LTSS, acute and behavioral health services. While the federal report mentioned earlier (Grimm 2020) suggests extensive room for improvement in how often this occurred in 2016, the system under the prior §1915(c) waiver was not set up to coordinate across types of care. Interviewees in our second round (Farnham, Chakravarty & Lloyd 2017) felt that there was improvement in care coordination.

Nevertheless, there were concerns expressed about access to the following types of services under MLTSS:

- 1) Access to or hours of private duty nursing (PDN) or personal care assistance (PCA), particularly for consumers with higher needs. Concerns covered:
 - a. the adequacy of assessments of needed hours,
 - b. availability of workforce to staff the hours,
 - c. reductions in hours, and
 - d. the notification and appeals processes regarding reductions in service.

- 2) Time needed for approval of caregivers under the Personal Preference Program (i.e., self-direction).²⁷
- 3) Gaps in some services, particularly social adult day services, non-medical transportation, (particularly in more sparsely populated areas), and direct care workers (including nurses to provide PDN as well as aides to provide home care assistance).
- 4) Home-delivered hot meals (as opposed to bulk home delivered meals).
- 5) Access to rehabilitative services for consumers with traumatic brain injury.
- 6) Redundant authorizations required for ongoing care.

Access to or assessed hours of private duty nursing (PDN) or personal care assistance (PCA).

Access to these services requires an initial assessment followed by continuing assessments by MCOs to provide service authorization for a number of hours, the availability of staff to fill the hours, and proper notification and appeals access in the case of reductions in the number of hours allowed. Interviewees noted problems with each aspect of access to these services. It's important to note (as advocate interviewees do) that they are not familiar with all cases but just noting those problems that are brought to their attention, and cannot know how common the cases they see are across the MLTSS population. Still, interviewees worried that consumers were often not in a good position to raise disputes (due to fear of losing services or lack of resources), and many felt that there should be more requirements before MCOs could reduce services (e.g., demonstrating that the consumer had improved from past assessments), and more transparency, surveillance and oversight of service reductions and MCO compliance with notification procedures.

- Assessments – Advocates question the validity of tools used for assessment as well as their implementation by MCOs, including a lack of transparency in sharing tool results. There is a standard PCA tool that all MCOs are required to use.²⁸ There is not a standardized tool for PDN, though interviewees (including MCOs) noted that MCOs use varied tools. Advocates were initially pleased to hear of standardization with the PCA tool. However, they were not involved in the tool's development and question whether it is valid or reliable (that is, whether it measures what it should be measuring to decide on hours allocation, and whether it would produce the same result if administered repeatedly). They note, for instance, that people do not do their toileting in blocks of time during the day. We have not seen any information on the development of any tools used for PCA or PDN, or studies on their validity or reliability. Advocates note that consumers

²⁷ State reviewers noted that they had not received feedback about this issue other than this report, and also noted that in response to the COVID-19 pandemic, an expedited enrollment process for workers/caregivers has been developed and is operating as of June 2020.

²⁸ The state does not post a copy of the tool, but this is a copy from a 2015 presentation <https://clpc.ucsf.edu/sites/clpc.ucsf.edu/files/NJ%20PCA%20Assessment%20Tool.pdf> (accessed June 25, 2020).

are not given a copy of the tool results, and that advocates have a difficult time getting a copy to examine when working with consumers. Advocates question the way tools are implemented, such as *“Performing PDN assessments by only reviewing nursing daily shift notes and without visiting the patient or speaking with the patient's caregivers, treating nurses or treating physicians. We believe that restricting assessments in this manner frequently causes the assessor to miss important medical and caregiver availability issues that result in an incomplete picture of the patient's skilled nursing needs.”* The PCA tool linked in the footnote above is supposed to be done in person and allows for flexibility in administration with the times shown as guidelines, but advocate experience is that the times are seen by MCOs as maximum amounts allowed. There are also questions with PDN about the extent to which monitoring of members by the nurse is allowed, versus time for hands-on care only—advocates note that regulations permit monitoring as long as there are hands-on skilled nursing needs in addition, but that MCOs disallow time for monitoring. Advocates also note that some MCOs perform reassessments more frequently than required (3 months rather than 6 months), which results *“in a continuing cycle of rapid reductions in PDN coverage followed by reversals on appeal [external IURO review] and then the same reductions occurring a short time after the reversal. ... Even if this problem does not ultimately result in a reduction of PDN services, it creates a great deal of unnecessary stress and uncertainty on patients and their caregivers who have to spend a lot of time and resources on appealing PDN decisions multiple times per year.”*

Several interviewees raised the need for some flexibility in assessment, possibly including allowing it to be for a longer time. One interviewee discussed a case they were aware of where a person had been transitioned out of an institution and then found clinically ineligible for MLTSS on their next assessment, by someone who was faithfully executing the assessment. The interviewee argued for considering not only the needs over the recent past, but the likely outcome if services were withdrawn: *“needs to be a more holistic assessment about that person's ability to remain in the community without services, or with limited services ... more relaxed standard, or a longer period of approval ... a lot of possibilities ... definitely something that should be explored ... [the assessment] doesn't adequately account for certain populations ... a lot of people with behavioral health needs ... having the provider come in is not just about providing for their physical needs, it's also about companionship, and stability, when people are just reassessed in this very black and white way that's based exclusively on the last 3 days, it just can't capture a lot of the realities that MLTSS recipients are living.”*

- Availability of staff to fill allocated hours -- Several interviewees noted problems in staffing awarded hours because of workforce issues with aides or nurses. For people with

complex conditions, having to piece together multiple providers can cause confusion. One interviewee noted: *"I'll have families that are having so much trouble finding private duty nursing, and then the MCO will cut the hours, because they can't find nursing ... it's just insult to injury."* The ultimate cause, they thought, was that the *"rate's not high enough."*

- Problems with the appeals process – Advocates all noted problems with the process of MCO notification of service cuts. Consumers only have 10 days to appeal for service continuation after the date on the letter received, and in many cases (potentially due to bulk mail service and/or MCOs not mailing the letter until after the date of the letter), consumers received the letter more than 10 days after the date printed on the letter. While advocates were able to help people in some of these cases, others experienced reduced benefits while their appeal was pending. Advocates reported that notification letters were often unclear and that they struggled to get documentation explaining service cuts. Further, they noted issues with documentation of early-stage internal appeals so that they could move on to the next stage of disputes (fair hearing or potentially external review in the case of PDN). State reviewers noted that while the state attempts to ensure appropriate access to appeals, the appeals process and timing are governed by the federal managed care rule, 42 C.F.R. § 438.400. Advocates concurred, noting that the federal rules had created problems.
- Reduction or denial of service hours. Many stakeholders (advocates, providers, and county/state agencies) perceived an increase in the propensity for consumers to face cuts in service hours of private duty nursing (PDN) or personal care assistance (PCA) under MLTSS, which was stressful for consumers and their families, even if the cuts were later reinstated. At the February 2020 MAAC meeting, an advocacy group brought a family that had experienced repeated PDN denials that had been overturned on appeal. After their testimony, a number of other advocates spoke up to say that they had seen similar cases with PDN or PCA. One advocate noted that when cuts in PDN coverage occur, MCOs do not assess clients for PCA eligibility or increases, leaving clients with *"drastic service reductions with virtually no time to prepare before the reductions go into effect."* Provider associations also reported concern about cuts in service. Several advocates noted that consumers faced continuing risks of hours reductions, even after having won appeals to past cuts. Interviewees noted that affected consumers may not complain because they are afraid of losing what services they have, or because they do not have the emotional or physical resources to do so. In a group interview where participants were discussing the importance of regular outreach to complex clients, one interviewee said *"most of the families I have that have kids that are on the waivers are ... really overwhelmed ... and they're really not going to put a lot into advocating for themselves, unfortunately."* A

provider association interviewee agreed that caregivers may not have the bandwidth to complain but also noted: *“there’s also a lot of fear, they’re afraid to complain, not that the state has ever, ever made it seem like they shouldn’t complain, or that they should be fearful, but still ... this is the lifeline, how they can survive their daily life ... heard parents say ‘Look, I’m grateful for the hours we get. It’s not enough hours, I know we’re authorized more hours, but I don’t want to rock the boat. God forbid they take my hours from me.’ Which, I say ‘no, they can’t take your hours from you.’ ‘Oh yeah? You want to bet they can’t take the hours? I’m sure they could. We don’t want to ...’ ‘So I’m like, okay.’”*

MCOs also expressed dissatisfaction with these processes. They noted that they were required to perform reassessments of consumers at least every 6 months, and that doing so with fidelity would frequently lead to a change in hours. They noted that the appeal processes are lengthy, harming their relationship with and thus the ability to manage the care of the consumer, that assessments were generally out of date by the time of the appeal, increasing the chance that the MCO assessment would be seen as incorrect (and that the process of disagreement would resume as soon as they did another assessment, further damaging the relationship with their member). They also felt that the people hearing appeals (independent utilization review clinicians or Administrative Law Judges) were not familiar with the Medicaid program and assumed that 24-hour home care was available (which would not be sustainable if widely implemented) and, in the case of Administrative Law Judges, lacked clinical expertise. So, while non-MCO interviewees generally had the view that rulings against MCOs by independent utilization review clinicians or Administrative Law Judges showed that the MCO was wrongly withholding services, MCOs did not agree with this view. MCOs acknowledged that they were overturned, but maintained that they were implementing the program as designed and in good faith. One of the MCO interviewees had been noted by other stakeholders as helpful in resolving disputes over hours. They acknowledged having asked care managers to take a broader look in some disputed cases (they did not issue a dictate), but they still took the MCO view noted above that MCOs were following the process as they should and that appeals overturning their assessments lacked clinical expertise or familiarity with the program.

An advocate noted that the question of hours of care had been an issue predating MLTSS, but was very important to consider when thinking about the quality of life of participants: *“even in the olden days when it was fee for service, ‘this program is not meant to provide services 24/7.’ Well, that’s not accurate legally, in my opinion ... they have to provide the services and supports that the person needs, as long as they can do that in a way that’s cost neutral, and that isn’t by the individual, that’s by the program. That’s part of the problem with the tools—the tools are not designed to really provide the care that the person needs ... [because they aggregate units of time that make it seem like people do everything consecutively] not really the way people live ... In the*

DD supports waiver, in the budgets, people can use some of their funds for DSPs, which aren't just focused on helping people complete [ADLs/IADLs] ... the state of New Jersey has overmedicalized, contrary to guidance from CMS ... the purpose of an HCBS waiver is to allow people to live their lives in the community, fully and integrated, and with doing the kinds of things they want to do ... consistent with ... cost neutrality ... if you go into a nursing home, there are social activities ... bingo, and crafts, and outings ... to help create a full life, and there really just isn't any of that in MLTSS. It's gotten more and more narrow as time has gone on. "

Approval of caregivers for self-direction. There were concerns about the time needed for approval of caregivers under the Personal Preference Program (i.e., self-direction), which has grown in popularity with MLTSS. According to interviewees, it generally takes two to six months for caregivers to be approved. Between the second and third round of interviews, administration of the Personal Preference Program moved from the Division of Disability Services to the Division of Medical Assistance and Health Services (both are within the Department of Human Services). State reviewers noted that they had not received feedback about this issue other than this report, and also noted that in response to the COVID-19 pandemic, an expedited enrollment process for workers/caregivers has been developed and is operating as of June 2020. The Personal Preference Program has grown substantially over time, from 30-50 new participants per month from 2008-2011, 75-100 per month with the inclusion of PCA services in Managed Care in 2011, up to a high of 955 new participants in June of 2020 (a total of 20,200 participants at that time, with average monthly growth of 409 participants, compared with a total of 15,687 participants in July 2019). The DMAHS report for Demonstration Year 7 noted an increase of 59% in enrollment-processing timeframes.²⁹

Gaps in MLTSS services. Several stakeholders noted that there were continued gaps in some services due to a lack of providers, particularly with respect to social adult day services, non-medical transportation, (particularly in more sparsely populated areas), and direct care workers, including nurses to provide private duty nursing. Gaps in these services have been noted since our first round of interviews. One interviewee in this round noted that in some cases nursing agencies substitute licensed practical nurses (LPNs), with less training, for Registered Nurses (RNs) and that families feel the LPNs are not adequately prepared to take on the complexity of their loved one's condition.

Home-delivered hot meals. The availability and importance of home delivered hot meals has been a topic discussed in our last two reports and was raised in one interview this time. Some feel home delivered hot meals are less of a burden for consumers than bulk frozen or shelf-stable

²⁹ Demonstration Year 8 annual report, pp4-5; Demonstration Year 7 annual report, pp.5-6

meals. Deliveries of hot meals occur daily, providing opportunities for someone to check in on the consumer's well being and for the consumer to have someone to talk with. We heard in past rounds that MCOs largely felt that bulk home delivered meals were a better value than a Meals on Wheels model, and not all past interviewees saw bulk meals as a negative. The 2018-2019 NCI-AD survey asked about home delivered meals,³⁰ and a total of 89 individuals responded (between 8 and 26 from each MCO). Almost all (83) reported knowing who to contact about their meals, and 68%-100% reported being satisfied with the meals. The most common reasons for lack of satisfaction reported by 15 respondents were other (not specified, n=8), lack of variety (n=6), poor quality (n=6), doesn't meet dietary requirements (n=4), and lack of ethnic food options (n=3). Between 42% and 75% of respondents per MCO reported having a choice between receiving their home delivered meals prepared daily or frozen in bulk twice a month. Reported satisfaction was higher in those MCOs where consumers reported having a choice in the type of meal received (type of meal received and preference for daily versus bulk was not recorded).

Access to rehabilitative services for consumers with traumatic brain injury. In the past two reports consumer advocates have noted awareness of consumers with traumatic brain injury who have been prematurely placed into custodial care, which may lead to lost opportunities to regain functioning and higher levels of independence. In some cases, social workers at custodial facilities have alerted them to such cases. They are not sure of the pathway into custodial care for these individuals (e.g., whether these are MLTSS MCO decisions, or whether other system gaps lead to custodial placement). We asked providers about this. While they were not aware of specific cases, one noted their perception that TBI units have constricted in the last 10 years, when they would think that the need would be constant or increasing.

Redundant authorizations required for ongoing care. One provider association noted that while authorizations made sense for nursing home care in cases where consumers were transitioning among different types of long-term care, they did not feel it made sense for residents who were spending down into Medicaid while not switching facilities, coming straight into a facility on MLTSS with no other services, returning to the same facility after a short term hospital stay, or having a lapse in redetermination despite never leaving the facility. In such cases, they argued "the requirement of authorization ... results in unwarranted gaps in payment for residents whose long term care eligibility is not in question." We have heard similar reports from other LTSS providers in past rounds (e.g., home care or medical day providers having to reauthorize services after a short-term hospitalization).

³⁰ See https://nci-ad.org/upload/state-reports/NJ_2018-2019_NCI-AD_state_report_FINAL.pdf , Tables 129-132.

Theme 2: Communication Among Stakeholders and State Regulation of MCOs

State Communication with Stakeholders. The state has a variety of ways of communicating with stakeholder audiences, as described in sections below.

- All Stakeholders. Until March of 2019, there was a quarterly MLTSS Steering Committee that predated and continued after MLTSS implementation with representation from providers, MCOs, consumer advocates, state officials, and technical assistance providers. Occasionally the group would form subcommittees, such as the Quality subcommittee concerning the planning of moving to “Any Willing Qualified Provider” participation in MLTSS.³¹ The Steering Committee has not been officially cancelled—an announcement was made upon cancellation of a planned October 2019 meeting that the state would look to reschedule within the next several months. Interviewees who had inquired told us that the state had suggested the Medical Assistance Advisory Council (MAAC)³² meetings, which are open to the public and generally quite large, as an alternative. Most consumer interviewees would prefer that the Steering Committee continue, as it was focused on MLTSS and better structured for conversation than the larger MAAC. One consumer-focused interviewee noted that they would get a response to issues brought up at the Steering Committee, but that since it had stopped meeting they were having a harder time getting answers. Another (who was not involved personally, but had contact with a participant) called its hiatus “disheartening.” Providers and MCOs were more neutral. One provider association interviewee thought it should continue but have transparency by health plans (potentially one at a time), with a deeper dive into issues reported by stakeholders. County agencies didn’t normally participate (although representatives from AAAs and County Welfare Agencies were included on the announcements). One interviewee thought that Special Child Health Services should be included if the committee were to reconvene, and another recommended Centers for Independent Living (a CIL representative is on the email list for the Steering Committee, but we never observed them participating). The state noted a lack of agenda items received as a reason to reduce the frequency of the meeting (from quarterly to biannual in 2019, though they noted this was not formally communicated to stakeholders), and then to decide that the MAAC was an acceptable forum for these topics.

³¹ See

<https://www.nj.gov/humanservices/doas/documents/NF%20Quality%20Incentive%20Payment%20Program%20October%202019%20Final.pdf> (accessed June 24, 2020).

³² See <https://www.state.nj.us/humanservices/dmahs/boards/maac/> (accessed June 24, 2020).

- MCOs. Representatives from the three MCOs interviewed expressed general satisfaction with their relationship with state officials, which include regular monthly or more frequent calls with each MCO. In all three rounds of interviews, interviewees with experience in other states note that New Jersey is a more engaged partner with MLTSS than other states they have worked with. One MCO interviewee noted that external quality review audit results were generally shared too late to be of much use in improving their work and that feedback from the NCI-AD was very slow to come, limiting their ability to learn from it before the next audit was underway.

Consistent with previous rounds, MCO interviewees generally expressed more satisfaction with their relationship with state officials than did non-MCO interviewees. However, it should be noted that state officials are in a different position vis-à-vis the MCOs compared with other stakeholders—the state is charged with regulating MCOs and does not have the same responsibility with other stakeholders. This may lead to more communication between the state and MCOs to monitor compliance. Also, as regulated entities, the MCOs may feel there is more to lose by criticizing the state, even in a confidential interview. However, MCOs are specific enough in their praise that we feel it is likely genuine.

- Providers. Provider interviewees noted a willingness by the state to convene workgroups or meetings when issues arose, though not always as quickly or meeting as frequently as they would like. Provider interviewees have mentioned several issues that have persisted for years (coordination of benefits issues and patient pay liability issues). One interviewee felt it was most productive to have meetings that included providers, the state, and MCOs in order to facilitate allocation of responsibility for addressing issues. There is a provider hotline with the state for managed care issues, which one interviewee said is overwhelmed with inquiries, though it has improved in responsiveness in the past year or two.
- Consumer Advocates. Other than the MLTSS Steering Committee and the MAAC, consumer advocates did not report any regular communication with the state. There is an MLTSS Quality hotline, which advocates working on individual cases find responsive (as an alternative to filing formal actions such as fair hearings, or independent utilization reviews) but which has become even less well publicized than in the past, when the phone number was on a Q&A document but not otherwise publicly posted. Advocate interviewees described asking for the number to be more publicized and being rebuffed by state officials afraid that they would be overwhelmed with calls. As mentioned earlier, most consumer interviewees would prefer that the Steering Committee continue, and

some would like to see more committee members from organizations that assist individuals with cases to facilitate discussion of issues.³³ Some consumer advocate interviewees were displeased when the state changed the design of the “Any Willing Qualified Provider” effort without consultation with the quality subcommittee or the greater Steering Committee (the changes involved incentive payments for meeting benchmarks separately). Providers we spoke with seemed to feel they had input and were happy with the changes, but some consumer advocates felt that the changes weakened the effort.

Other inter-stakeholder communications. We have heard of several examples of other inter-stakeholder communications regarding MLTSS:

- MCO Contract requirements.
 - Each MCO is required to have several advisory committees (general Community, Provider, and MLTSS Consumer). We talked with one MCO about their consumer advisory committee, which they said was for all Medicaid consumers but contained MLTSS-related members. We spoke with an MLTSS-related member of an MCO’s committee, who found it useful. Generally, there is little public information about the makeup or activities of these committees.
 - Each MCO is also required to have a “full-time designated MLTSS Member Representative responsible for internal representation of the interests of MLTSS Members ... The MLTSS Member Representative shall assist MLTSS Members in navigating the Contractor’s system...”³⁴ One MCO mentioned they had more than one such representative, and in our previous rounds of interviews we have heard of the Member Representative making contact with community organizations and facilitating the provider network in addition to helping members. In late 2019 a member representative from one MCO presented at a national conference with staff from the NJ Office of the Long-Term Care Ombudsman about their collective advocacy (Bailey, Cianfrone & Brewer 2019).
- At least one county agency has organized a quarterly meeting in their county with participants from the AAA/ADRC, County Welfare Agency, OCCO, and MCOs to discuss issues relevant to providing services to people in need of LTSS.
- One consumer-related advocate organizes occasional meetings to discuss relevant issues with a variety of other consumer advocates.

³³ There was a representative from Legal Services of NJ on the Steering Committee starting in 2015. Other potentially relevant advocacy organizations would be Disability Rights NJ and the Community Health Law Project.

³⁴ See Article 7, page 5 of the 1/2020 accepted MCO contract

<https://www.state.nj.us/humanservices/dmahs/info/resources/care/hmo-contract.pdf> (accessed June 25, 2020).

- We have observed that provider associations facilitate state communication about policies or programs (webinars, presentations, etc.)

State regulation of MCOs. As in our previous reports, many stakeholders continue to feel that the state is too deferential to the MCOs. One noted: *“New Jersey Medicaid definitely has a culture of deferring to the MCOs, and wanting to please them ... and not rock the boat ... much more, I think, than in other states, ... there’s a lot of carrots, but there seems to be no sticks ... very rarely [mentioned Fall 2019 blocked enrollment at one MCO] ... concerns me, and I think concerns a lot of people who are trying to see more systemic changes, better services, better care... I don’t think the services or the care ... in New Jersey ... is bad, it just seems ... a lot of deference to MCOs ... something I wish would change.”* They noted “some movement” in a positive direction.

In November of 2019, the state froze enrollment in one MCO “because of operational and quality issues related to program standards and contract requirements.”³⁵ As of the end of June, the freeze was still in place.³⁶ Regulatory actions may not be made public. A 2017 attempt by the press to gain access to documentation of a Department of Human Services sanction of an MCO, after it was announced publicly by the governor, was rejected by a court order (Livio 2017).

In addition to their overall sense of lack of assertive regulation, stakeholders complained of lack of transparency with regard to quality reporting and individual budget amounts.

- Transparency on quality reporting, including spending. Stakeholders complain about a lack of transparency on quality and regulatory issues, and are not always able to get documentation of issues that are of interest to them (items mentioned this time included service reductions, hours awarded but not filled, state spending (as opposed to claims dollars), and TBI specific information). The state envisioned and tracks a set of about 40 MLTSS quality metrics (DMAHS 2014), reported by a mix of MCO and state agencies and with differing frequencies and lag times (some are monthly; others are annually with a 6 month lag for claims run out plus an additional month to calculate the metric). Early on, the state developed a separate quality-focused meeting for MCOs and state subject matter experts because it was clear that the initial plan-reported metrics were not comparable. Subsequently, the state involved an external quality review organization to standardize the data. The state posts or links to results from external quality review organization audits and the NCI-AD survey on quality of life.³⁷ One MCO would like

³⁵ See http://www.njfamilycare.org/docs/United_FAQ_%20FINAL_10_%2029_%2019.pdf (accessed June 25, 2020).

³⁶ Noted at <http://www.njfamilycare.org/default.aspx> (accessed June 25, 2020).

³⁷ See <https://www.nj.gov/humanservices/dmahs/home/mltss.html> (accessed June 25, 2020).

results/feedback sooner for these items. Some waiver-related reporting can be found at the CMS web site.³⁸

- Transparency on individual budgets. Interviewees have also repeatedly mentioned a concern about lack of transparency on individual budgets. Advocates recall that in past waiver programs people knew what their budgets and service costs were and there was transparency as to whether they were approaching the limit of their budget. Now, MCOs are required to calculate how close MLTSS members are to their cost threshold and to call an interdisciplinary team meeting to discuss needed services with state personnel, the MCO and the member if members are close to the threshold. The cost-effectiveness analysis is part of the care plan and shared with members.³⁹ Advocates are concerned that there is no way for anyone outside the state or the MCOs to verify the proximity to the cost limit, potentially putting MCOs in a position to minimize service costs and keep the extra funds. State staff told us in past rounds that they do not want to encourage a mindset they have observed in some past cases where people, knowing their maximum budget, may try to get as many services as they possibly can, rather than what they actually need. Since provider rates may differ by MCO, the cost of services is not as easily calculated as under the fee-for-service system.

Theme 3: Reflections on LTSS Design

Questioning the Inherent Incentives of an MLTSS System. A number of interviewees were concerned that a managed care arrangement means that MCOs have incentives to skimp on services to increase revenue. They did not believe that medical loss ratio requirements mitigated these incentives enough. A couple of interviewees were also concerned that perhaps MCOs tried to enroll people with lower needs for services in order to increase their revenue. Several interviewees brought up other states (in particular Connecticut and New York) that have made decisions to move away from managed care arrangements: *“how is the money being distributed ... hundreds of millions of dollars ... are we getting ... the best bang for the buck? We have seen some other states move away from MLTSS ... because audits were revealing that it wasn’t necessarily turning out to be the most cost-effective way to deliver the highest quality of benefits ... without that kind of analysis, that question is still out there. This is still a demonstration project,*

³⁸ See <https://www.medicaid.gov/medicaid/section-1115-demo/demonstration-and-waiver-list/82571> (accessed June 25, 2020).

³⁹ See MCO contract 9.3.2 on the details of the cost effectiveness analysis and specific notification requirements of any adverse action taken, or discussions required when the threshold is approached. The analysis is part of the care management record detailed in 9.2.2B and part of the care plan detailed in 9.6.4K that is required to be shared with the member.

and that is one of the questions we are trying to answer, and without understanding that, how do we effectively answer that question?"

- *Service reductions or minimization?* Concerns about this were noted extensively above in Theme 1.3. In addition to advocates who work on behalf of clients whose benefits have been reduced, interviewees who were not engaged in advocacy also expressed hesitation about potential MCO motivation to reduce services. One county agency staff member noted that s/he was leery from the beginning since the system of MCOs determining service access seemed like “the fox guarding the henhouse.” S/he attends Medical Assistance Advisory Council meetings and “cringes” when s/he hears stories there about service reductions and client suffering, wondering how often that occurs. S/he didn’t feel there was ample evidence that MCOs provided adequate services. However, as was also discussed above, MCOs noted that it is required that they assess members at regular intervals, and felt that doing so with fidelity would lead to changes in approved hours. Utilization management is a feature of managed care, and judgements of when it is imposed inappropriately are subject to dispute.
- *Overenrollment?* A couple of interviewees noted a state auditor’s report issued in November of 2018 as they expressed concern that MCOs may be enrolling people with few needs to increase their revenue (see Eells 2018). The response at the end of the 2018 auditor’s report notes that Medicaid’s analysis done in response to the audit showed that shifting the individuals flagged as potentially inappropriate in the audit from MLTSS to the regular ABD population would have driven up capitated rates in both groups⁴⁰ and thus would not have changed the state’s financial outlay appreciably. The audit also discussed an automatic algorithm that enrolled anyone meeting both financial and clinical eligibility into MLTSS (regardless of whether they have requested services or been identified by an MCO). This algorithm is a state decision to enroll eligible individuals (made to proactively identify those who are eligible and at risk of needing LTSS and prevent enrollment delays). MCOs have a responsibility to obtain consent from enrollees, provide counseling on the program requirements, and ensure continuing eligibility among those enrolled, which they did not always do. The most recent contract tightens requirements in this regard.

ASO as Alternative Design. Two interviewees pointed to the Administrative Service Organization (ASO) design in Connecticut as a potential alternative to deliver services with potentially lower administrative costs and no incentive to minimize services for the sake of revenue. Connecticut never had MLTSS, but did move beneficiaries from acute managed care into an ASO. It has

⁴⁰ The rate in the ABD group would go up because these members had higher service use relative to the ABD group. The rate in the MLTSS group would have gone up because the lower service users were removed, so the average service use would be higher.

separate ASOs for medical, dental, behavioral health, and transportation services.⁴¹ It is not clear to us what (if any) role the ASOs play in the administration of LTSS in Connecticut.⁴² New Jersey currently has an ASO design in its Children’s System of Care (CSOC) under the Department of Children and Families.⁴³ The two who suggested the ASO design as a model did not have an opinion about CSOC, though one of them directed us to another stakeholder for an opinion. The stakeholder to whom we were directed noted that, while the ASO model was preferable to the MCO model because it doesn’t have the incentive to reduce or limit care, there could still be problems with lack of knowledge or resources to provide care in an ASO model.

Nursing Home Care in MLTSS. As noted earlier, there was fairly widespread dissatisfaction among nursing home care management expressed among stakeholders (among those who commented on this issue). An MCO interviewee noted that other states have lower numbers of members per care manager, allowing for more attention to members, and thought the NJ contract should be changed to allow MCOs to bring in more care managers.⁴⁴ When asked why the MCO couldn’t just hire more care managers, given that the contract doesn’t prohibit a lower ratio, the interviewee noted that this type of decision was a financial one driven by others in the organization and that they would not be allowed to hire more than the number of care managers required by the contract (this interviewee wanted a large change in the ratio, so it would be noticeable). An interviewee from the provider community noted that New York had decided to remove nursing homes from MLTSS and they believed New Jersey should do the same.⁴⁵ Another interviewee from the provider community wasn’t sure they agreed with the removal of nursing homes from MLTSS but knew of the opinion and thought the discussion should be had—this

⁴¹ For an overview, see <https://portal.ct.gov/-/media/Departments-and-Agencies/DSS/Communications/Overview-of-HUSKY-Health---consolidated-issue-briefs-9-12-18.pdf?la=en> (accessed June 23, 2020).

⁴² See

https://www.cga.ct.gov/ph/med/related/20190106_Council%20Meetings%20&%20Presentations/20200214/HUSKY%20Financial%20Trends%20February%202020.pdf for a recent discussion of CT Medicaid costs (including LTSS) and

https://www.cga.ct.gov/ph/med/related/20190106_Council%20Meetings%20&%20Presentations/20181012/DSS%20Division%20of%20Health%20Services%20Community%20Options%20Presentation%201012.pdf for a presentation on LTSS (accessed June 23, 2020).

⁴³ See <http://www.performcarenj.org/index.aspx> (accessed June 23, 2020).

⁴⁴ In Florida, ratios are 1:100 for members in nursing facilities if 21+, 1:60 in community settings, 1:40 private duty nursing, and 1:15 for children in special care nursing facilities (see pp62-63, [https://ahca.myflorida.com/Medicaid/statewide_mc/pdf/Contracts/2018-02-01/EXHIBIT_II-B_Long_term_Care_\(LTC\)_Managed_Care_Program_Feb_1_2018.pdf](https://ahca.myflorida.com/Medicaid/statewide_mc/pdf/Contracts/2018-02-01/EXHIBIT_II-B_Long_term_Care_(LTC)_Managed_Care_Program_Feb_1_2018.pdf)); in Hawai’i, ratios are 1:120 in institutional settings and 1:50 in home and community based settings (see p.L-13, https://medquest.hawaii.gov/content/dam/formsanddocuments/resources/RFP/QIRFP-MQD-2014-005APPENDICES_rev09-20-19.pdf); an email from an MCO that was in discussions to provide MLTSS in North Carolina before it delayed implementation said that the requirement there was to be 1:120 in institutional settings (we could not find state documents to verify the ratio because implementation is delayed for now).

⁴⁵ See <https://skillednursingnews.com/2020/01/new-york-to-pull-nursing-home-residents-out-of-managed-medicare-while-also-pursuing-more-spending-cuts/> (accessed June 16, 2020).

interviewee felt that while there was potential value in having someone outside the nursing home involved in care planning, MCO care management in nursing homes had not improved over time, to the point where it wasn't clear that there was any outside planning. Even the interviewee who thought MCO care managers had achieved more visibility in nursing homes since our last report in 2016 also noted that nursing home care was mostly out of MCO control, and that the nursing home manages care with oversight mostly located outside MCOs. Our last report noted that some advocates felt that there wasn't any incentive for MCOs to reduce nursing home use because the rates were determined by the state, making it a pass-through and possibly leading MCOs to look at minimizing costs in HCBS. An MCO interviewee this time commented that because resources overwhelmingly go toward nursing home care and there are still any willing provider requirements there, there wasn't much room for MCOs to move the needle on quality with HCBS (by offering incentives, for example). A consumer advocate disagreed with the idea of moving nursing home care out of MLTSS, reasoning that if that were to occur, MCOs would encourage expensive enrollees to utilize nursing home care to get them off their books.

Preventing Institutional Care. One consumer advocate suggested a different level of care requirement for home and community based services to prevent institutionalization. While the advocate is pleased with the inclusion in the regular Medicaid state plan of PCA and medical day, only very low income people can access these services, while slightly higher income people who can qualify for MLTSS if they have an institutional level of care have to wait until then to access services.

Theme 4: Broader LTSS Environment

In addition to the themes noted above which pertain directly to MLTSS, there are a number of issues in the broader LTSS environment that affect MLTSS-related organizations and members that were raised in our interviews. These include:

- 1) Nationwide shortages of direct care workers and nurses
- 2) Problematic linkages/gaps in communication
- 3) Gaps/lack of role clarity in the social safety net
- 4) Remaining silos between programs

Shortages of Direct Care Workers and Nurses. There has been a nationwide shortage of both direct care workers and nurses for a number of years (Gifford 2019, U.S. Department of Health and Human Services 2017).

Direct care work is difficult, low-paid, and the hours for home care aides in particular (as opposed to aides in facility settings) tend to be fragmented, making it difficult to piece together full-time

work. Workforce shortages tend to be exacerbated in areas with high travel times and a lack of public transportation, because this increases workers' transportation costs. Our interviewees indicated that this shortage had not abated, and that legislative efforts to ensure adequate compensation for aides, while needed and well-intentioned, had further strained agencies who have to cover all of their overhead costs from the rate MCOs pay them, which is tied to aide hours (as noted in previous reports, agencies can no longer bill separately for nursing assessments and supervisory visits). The Personal Preference Program (PPP, noted in Theme 1.3 with regard to concerns about time needed for approval) allows consumers to hire and direct their own caregivers. Interviewees indicated that this complicated their relationship with aides, who may leave agency employment temporarily to make more money working directly for consumers, but then return to obtain recertification so that they retain the option of working with an agency.

The nursing shortage affects MLTSS in several ways. It drives up costs and/or complicates recruitment for all organizations that utilize nurses, including service providers, MCOs, and OCCO. It makes it difficult to staff private duty nursing cases. One interviewee felt that the rate paid was an important factor *"The biggest issue is the lack of availability of nursing. Some of the families have no nursing at all. One has a wound that now requires surgical intervention, perhaps if this youth had had nursing this would not have happened. This was a major problem at one point in the past, the state raised the rate it paid nurses and it became much easier to staff. That was probably 10 years ago."*

Problematic linkages/gaps in communication. A number of organizations are involved in the enrollment, maintenance, or renewal of consumers with MLTSS. In some cases organizations have to exchange information or consumers have to wait before the next step, which creates opportunities for consumers to experience delays in services. We heard about problems with the following:

- *Determining when clinical and financial eligibility pieces are complete* – several interviewees identified this as a problem, noting that if it weren't for their follow up and troubleshooting, applicants would be adrift in trying to ascertain the status of their application. Clinical and financial eligibility can be completed in any order. The Office of Community Choice Options (OCCO) assesses MLTSS applicants new to Medicaid and has had challenges with assessment timeliness due to resource constraints since MLTSS began (see Eels 2018, Chakravarty et al. 2017), which several interviewees indicated was still an issue. County welfare agencies manage financial eligibility determinations. The state and counties have streamlined the process to allow for an online application,⁴⁶ but

⁴⁶ See <https://www.state.nj.us/humanservices/dmahs/clients/medicaid/abd/> (accessed June 24, 2020).

agencies have to take a deep look into applicants' finances over the preceding 5 years,⁴⁷ so decisions are not instantaneous. At the inception of MLTSS, county welfare agencies were given access to information on clinical eligibility status, but it is burdensome for them to access, and we have heard different things from different counties about the extent to which they are notified when clinical eligibility is complete. This time, one agency said they are notified by OCCO of this; another said that the system was still "awkward and confusing" for them.

- *Waiting for enrollment after eligibility is complete* – MCO enrollment can only start on the first of the month. There is a cutoff each month for the next months' start, which varies by month due to holiday schedules, etc., but it can be 6 weeks between the time that eligibility is determined and MCO enrollment starts. One interviewee told us there is a manual way to intervene in some cases to decrease waiting time, though they can never backdate MCO enrollment. During the period after eligibility is complete but before MCO enrollment begins, enrollees are eligible for state plan services such as medical day and personal care assistance through a fee-for-service arrangement, but interviewees said that consumers were not notified of this.
- *Redeterminations* – as mentioned earlier, consumers can be dropped from Medicaid if they do not complete their redetermination paperwork with the county welfare office. County welfare agency staff still reported not knowing who to contact at MCOs for assistance in finding nonrespondents, and as noted earlier one MCO would like to know if any of their enrollees haven't responded so that they could follow up. State officials noted that a list had been developed to address the communication issue between MCOs and CWAs, that discussions had been held to communicate that it was not a HIPAA violation for the MCO and CWA to speak about eligibility, and that MCOs are contractually required to work with members on redeterminations, specifically "monitor financial eligibility terminations and alert the Care Manager to coordinate the transition of Members from the MLTSS program to available community services and resources to meet the needs of Members in advance of the termination including outreach to the CWA, filing for a fair hearing, and assistance with completion of financial redetermination requirements to delay the termination when appropriate."⁴⁸
- *Managing the Patient Pay Liability (PPL) for consumers in Assisted Living* – depending on their income and expenses, consumers in assisted living have a varying amount of patient pay liability, which is computed by county welfare agencies and communicated to MCOs,

⁴⁷ Applicants with very low levels of resources can self-attest to not making any transfers as an alternative to undergoing the 5 year lookback.

⁴⁸ From 9.6.6 (B) of MCO Contract Amended 1/2020, accessed from <https://www.nj.gov/humanservices/dmahs/info/resources/care/hmo-contract.pdf>

who then have to communicate the information to providers.⁴⁹ One interviewee noted that this can be complicated and result in retroactive liability, that the MCOs are not set up to do this, and that this results in delays and providers having to pursue consumers or their families for funds, sometimes without results. Waiting by consumers/families for notification of the amount can lead to a buildup in assets that could make them ineligible for Medicaid. While our interviewee didn't know of a case where this had happened and our county welfare agency contact told us that this could be managed without loss of eligibility, our provider interviewee noted that it was a stressor for enrollees or their families.

Gaps/lack of role clarity in the social safety net. It is important to note that the social safety net was subject to gaps and participant confusion over roles prior to MLTSS. Also, budgets for social services have often remained constant as demand has grown. Several interviewees throughout our three rounds of interviews have discussed gaps or lack of clarity around roles that have occurred when care management transitioned from community based organizations to MCOs. In some cases, the positions at community based organizations went away and there is no longer anyone to continue to work with consumers getting MLTSS. However, in other cases these positions have remained, and these workers struggle to advocate for clients with MCOs, because they are no longer official providers. One interviewee mentioned that Centers for Independent Living are not responded to when they try to advocate for their clients, compared with other organizations such as AAAs, who are more formally included in the system because they are tasked with doing screens for community services (this interviewee was not with a CIL, but interacts with staff from CILs and AAAs). In some cases they feel there are actions MCOs should be taking for clients that they apparently are not, such as informing clients about NJ Register Ready⁵⁰ to notify emergency responders about people with disabilities, or checking on clients with the onset of the COVID-19 pandemic. One interviewee noted, *“Since the program has left [organization], it seems like no one is advocating for the families.”* One interviewee noted that different counties have made different decisions about the level of staffing to continue, which may mean that consumers in non-staffed counties are going unnoticed if there are problems with their care.

Remaining silos between programs. Most interviewees are happy with the silos that have been broken down with MLTSS, as discussed earlier. However, two interviewees noted some ongoing restrictions that they feel keep consumers from getting proper care:

- One noted that children enrolled in MLTSS cannot get services from PerformCare, the Children's System of Care, because all services are considered duplicative. This

⁴⁹ See https://www.state.nj.us/humanservices/dmahs/home/MLTSS_Residential.pdf (accessed June 24, 2020).

⁵⁰ See <https://www13.state.nj.us/SpecialNeeds/> (accessed June 24, 2020).

interviewee felt that there were some services offered by PerformCare that are not offered under MLTSS. They had begun to talk with state officials about this.

- Another brought up a situation a family they worked with was in: *“The most frustrating situation I have is a family that has been repeatedly told by their care manager that they cannot have services under PPP (Personal Preference Program) and Private Duty Nursing. They have no private duty nursing so the parent is unable to work so the parent’s only option is to be part of the Personal Preference Program.”* State reviewers noted that this was not true—that members could be part of both PPP and have PDN, as long as the services don’t overlap.

Conclusions

This report is designed to describe the viewpoints of stakeholders regarding managed long-term services and supports (MLTSS) in New Jersey, and is the third in a series of reports based on interviews with a variety of stakeholders as well as review of program-related documents and observation of meetings relating to MLTSS (see also Farnham, Chakravarty & Lloyd 2017; Farnham, Chakravarty & Lloyd 2015). This report includes 18 interviews with 26 key informants conducted from April through June 2020. A total of 89 individuals participated in either individual or group interviews between the three rounds of interviews.

Interviewees included representatives of state agencies involved in MLTSS implementation, managed care organizations participating in MLTSS, advocacy groups for older adults and younger people with disabilities, providers of LTSS, and agencies or associations of agencies that work with MLTSS enrollees in a variety of contexts and in some cases provided case management services under the former §1915(c) waivers (e.g., county welfare agencies, Area Agencies on Aging, Centers for Independent Living, and Special Child Health Case Management). To protect the confidentiality of our interviewees, we do not list the names or specific organizations of those with whom we spoke.

Our analysis shows that while interviewees are happy about increased enrollment and the breaking down of silos inherent in having unified services under MLTSS, questions remain about the quality of care management and access to services, particularly those requiring ongoing assessment and potentially varying hours of care, such as private duty nursing and personal care assistance. Workforce shortages compound the issue of potential service minimization by MCOs.

Many stakeholders continue to feel that the state is too deferential to the MCOs. MCO interviewees reported the highest level of satisfaction with their relationship with state officials, with providers somewhat behind and consumer advocates considerably further behind.

Consumer advocates in particular would like to see the reinstatement of the MLTSS Steering Committee, which provided a forum for discussion.

Some still question the desirability of a managed care model for MLTSS, and some question the inclusion of nursing homes in MLTSS.

There are a number of issues in the broader LTSS environment that affect MLTSS-related organizations and members such as workforce shortages, problematic linkages between organizations or gaps in communication that complicate Medicaid enrollment and redetermination, gaps or lack of role clarity in the social safety net which in some cases have been complicated with the addition of MCOs, and remaining silos between programs that prevent consumers from getting the best possible services.

To some degree, perceptions vary by stakeholder role. For instance, providers seem to have been impacted negatively by MLTSS, with rate reductions, increased administrative burden with contracting, credentialing, obtaining authorizations, and filing claims with 5 MCOs instead of a single payer, and longer wait times for payments.

Advocates encounter people who are having problems with MLTSS and detailed many issues with still-fragmented systems, service reductions and gaps, lack of proper care management, lack of data-sharing and transparency, and to some degree the lack of advocate involvement in stakeholder and policy discussions.

MCOs reported being generally satisfied with their relationships with the state and others. Together with advocates, they think that the fair hearing process is too lengthy. One would like faster feedback about quality initiatives to allow them to address any problems in a more timely way.

State staff remain determined to make the program work with the resources they have available and remain committed to a philosophy of continual improvement. Advocates and providers generally seem to feel that problems that they identify to state staff are addressed and usually resolved, but in many cases feel that there was too much effort expended on their part or that they had to know who specifically to contact in a way that the average consumer, particularly the vulnerable populations that tend to be receiving MLTSS, would not be able to.

All stakeholders feel that data that might provide answers to some advocates' concerns about how quickly people are able to access services, gaps in services, and participants' well-being have been slower in coming than would be desired. The state continues to work with an external

quality review organization, the NCI-AD, and planning their own audits and data collection to address such questions. Scholars have noted the difficulty of measuring quality in LTSS, so New Jersey is not unique in experiencing this issue (Thomas and Appelbaum 2015).

When evaluating how the system of care has changed with MLTSS, it is important to keep in mind that limited comparative information exists on processes and outcomes in pre/post MLTSS, that MLTSS is implemented somewhat differently in each of 5 MCOs, and that MLTSS may have different effects on different groups of consumers.

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Appendix: MLTSS Interview Guide, Round 3 Interviews

(Note: Subquestions 1.1-1.11 were distributed to MCO interviewees only)

MLTSS Interview Guide, MCOs, Renewal Interviews

1. **First, can I get a sense of how you get information about how MLTSS is going?**
 - 1.1. Enrollment. How is the process of enrolling consumers going? Are you satisfied with the way consumers are assigned to MCOs or given information to choose an MCO? How often are there switches between plans? How difficult is it to ensure continuity of services during switches?
 - 1.2. Care management. How has your experience been with recruiting/retaining care managers? How is the care management experience going—are there any barriers to effective care management?
 - 1.3. Quality measurement. How do you measure the quality of services (care management and other services) that your members receive? Would you see any overarching role in facilitating measurement of provider quality comparable to what the state has done in developing standard billing codes and credentialing? What do you think of the MLTSS Quality Metrics for which you report data? Are there any that you think are particularly relevant for assessing quality and access to care?
 - 1.4. Assessment tools. How is the process of using the NJ Choice and the PCA tool going (tool itself, communications regarding data in the tool, etc.)?
 - 1.5. Appeals/Grievances/Complaints/Utilization Reviews/Fair Hearings. How are things going with disagreements with consumers or providers? Any trends, items of note, or ideas for process improvements in this area?
 - 1.6. Providers. How are things going with establishment/maintenance of provider networks for LTSS and behavioral health? Has the provider population changed over time (consolidation, etc.)? Are there any gaps (service wise, region wise, etc.)? What are the reasons for these gaps? How are self-directed services fitting in with this?
 - 1.7. Transitions. How are things going with transitions among settings, particularly out of nursing facilities to community settings? Any barriers encountered to effective transitions?
 - 1.8. Cost Caps/IDT process. Are you seeing many consumers hit the cost caps with community services? How do you monitor costs? Are there barriers to an effective IDT process?
 - 1.9. Information technology. Modern operations depend heavily on IT. Have you had any issues with IT in your MLTSS operation?
 - 1.10. Consumer Advisory Committee: Do you have an MLTSS Consumer Advisory Committee? How do you find committee members and develop topics or agenda items for the meetings?
 - 1.11. Other MCO issues. Self attestation forms of no asset transfers for those who are MCO-enrolled prior to MLTSS eligibility. How is this working? Any other issues specific to the MCO role?
2. **Have the changes with MLTSS benefitted any population or patient groups? Have they caused difficulty? How?**
 - 2.1. Has it affected the experiences of consumers in accessing services (initial information and referral, clinical and financial eligibility determinations, time for services to start)? How? How

have non-MCO organizations serving the same populations (e.g., AAAs, CILs, OCCO, etc.) been affected by MLTSS?

2.2. Has it affected the types of services consumers receive? How?

2.3. Has it affected the hours of services consumers receive? How?

2.4. Has the placement of the care management function in the MCOs affected the consumer experience? How?

2.5. Has continuity of care been affected by MLTSS (e.g., availability or turnover among care managers or providers, service authorization policy/procedure, etc.)?

2.6. Has there been any change in the opportunity for consumers to direct their own services under MLTSS?

2.7. Has the process of transitioning from facilities to community settings changed under MLTSS? How?

2.8. Are you aware of any cases where it is more difficult to keep people in community settings under MLTSS? How typical is this?

- 3. Since MLTSS was implemented, have you noted any changes in the health of specific population groups that you work with? Please describe.**
- 4. Have you seen any changes not mentioned previously in LTSS providers since the changeover to managed care began in 2011? How do you think MLTSS is affecting the various LTSS providers that serve consumers?**
 - 4.1. Have there been changes/expected changes to payment rates received by providers or other relevant factors under MCOs? What has this meant for providers and consumers?*
- 5. Have you seen new clinical or community partnerships that have developed to support MLTSS?**
 - 5.1. For example, in a presentation to the MLTSS Steering Committee, one MCO described trying to shore up the social safety net in communities that seemed to have gaps. Do you see this happening?*
- 6. What do you think are the key data that should be examined regarding the effectiveness of MLTSS? Are these data being collected? If not, what would the data source(s) be?**
 - 6.1. Have you reviewed data presented at the MAAC or MLTSS Steering Committee, the NCI-AD results, or evaluation reports? Do you have any feedback about these?*
- 7. Have you seen MLTSS evolve since 2014? How? Are there additional supports or improvements that are needed to make MLTSS successful? If so, what are they?**
- 8. Is there anything else relevant to the evaluation of MLTSS that I haven't asked you about?**



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