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Implementation of Medicaid Managed Long-term Services and Supports for Adults with Intellectual and/or Developmental Disabilities: A State's Experience

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Implementation of Medicaid Managed Long-term Services and Supports for Adults with
Intellectual and/or Developmental Disabilities: A State's Experience

by

Heather Jeanne Williamson

A dissertation submitted in partial fulfillment
of the requirements for the degree of
Doctor of Public Health
Department of Community and Family Health
with a concentration in Behavioral Health
College of Public Health
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DEDICATION

This dissertation is dedicated to my husband Chad for always encouraging me to take risks and supporting my successes and failures along the way.

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ABSTRACT

Background: Individuals with intellectual and/or developmental disabilities (IDD) are experiencing longer life expectancies with the majority requiring the ongoing support of family caregivers into adulthood. Medicaid is the primary funding source for supports and services for adults with IDD. Growing Medicaid expenditures and goals to improve quality of care are driving more states to move their Medicaid fee-for-service programs into a managed care model. The stated goals of Medicaid managed long-term services and supports (MLTSS) are to improve care coordination and access to care while controlling costs, but the evidence regarding these outcomes is limited and mixed. Given the level of uncertainty about MLTSS for adults with IDD and their family caregivers, best practices recommendations have been produced by the federal government and advocacy agencies to help guide future MLTSS implementation efforts. These best practice recommendations combined with the continued expansion of MLTSS in the states, provided an opportunity to further explore implementation of MLTSS to inform both policy and practice. One state which recently reformed their Medicaid program to MLTSS and which has been referred to as a bellwether state is Kansas. The MLTSS program in Kansas, titled “KanCare”, is the first for adults with IDD to integrate across health, behavioral health, and LTSS while also contracting through three private-for-profit managed care organizations (MCOs).

Aims: The objective of this study was to describe the current implementation of MLTSS for adults with IDD and their family caregivers in one state, Kansas. Study aims were as follows: 1) To understand the rationale behind and what actually happened with MLTSS implementation for

adults with IDD in Kansas; 2) To understand how service coordination providers and family caregivers perceived care coordination and access to services for adults with IDD in MLTSS; 3) To understand how family caregivers and their roles were recognized in MLTSS for adults with IDD.

Methods: A single case embedded design case study approach was used with in-depth semi-structured interviews completed with state/regional level representatives (N=13), MLTSS service coordination providers (N=7), and family caregivers of adults with IDD (N=11). Data collection and analysis were guided by the unified theory of family quality of life (FQOL) and Bronfenbrenner's ecological model. The framework method was used to structure the data analysis process. Member checking was completed to ensure accuracy of results.

Findings: Regarding aim one, respondents identified reducing costs and improving care quality as the rationale behind MLTSS, but these were outcomes not yet realized given the early stages of implementation. At the time of this study, the Managed Care Organizations (MCOs) were continuing to work on expanding provider networks and to provide additional services to address health disparities amongst individuals with IDD. Study participants identified the importance of adequate planning and stakeholder engagement to reduce confusion and fear when transitioning into MLTSS. Addressing aim two, timely and accessible consumer education, clear care coordination processes, and provider network adequacy were identified as important to influence the challenges experienced to date in care coordination and access to services. Regarding aim three, participants acknowledged the important role of family caregivers. At the current stage of the KanCare implementation, participants reported lack of formal processes for family caregiver assessment and a need for more proactive family support services planning.

Conclusion: Lessons learned from this implementation experience include the importance of having long planning timelines and including stakeholder feedback into the design of MLTSS programs. Care coordination holds promise to better integrate care, but more research is needed to understand best practices for the provision of care coordination in MLTSS. In order to address access to services, MLTSS programs will need to work and build provider capacity and provider networks. MLTSS programs will also need to formally recognize the role of family caregivers by incorporating the use of family caregiver assessments to proactively plan for support needs.

SECTION I: INTRODUCTION AND THEORETICAL FRAMEWORK

Statement of Problem

Adults with intellectual and/or developmental disabilities (IDD) have complex needs. An intellectual disability is a disability diagnosed before age 18 which involves difficulty with intellectual functioning and completing adaptive behaviors (social and practical skills). A developmental disability is diagnosed before the age of 22 and involves having a physical impairment or a cognitive impairment or both (American Association on Intellectual and Developmental Disabilities, 2013). In practice, developmental disability includes intellectual disability, so the groups are classified together and referred to collectively as intellectual and/or developmental disability or IDD. Common categories of IDD include Down syndrome, Autism, and Cerebral Palsy. It is estimated that 1.5 to 2.5% or 4.6 to 7.7 million people in the U.S. are currently diagnosed with an IDD (Morstad, 2012).

The complex needs experienced by adults with IDD are further complicated by health disparities and comorbid conditions. Individuals with IDD experience poorer health than the general population and have higher rates of chronic conditions (Beange, Mcelduff, & Baker, 1995; Centers for Medicare and Medicaid Services, 2013a; Corbin, Holder, & Engstrom, 2005; Croen, Zerbo, Ouan, & Massolo, 2014; Hensel, Rose, Kroese, & Banks-Smith, 2002; Krahn, Hammond, & Turner, 2006; Krahn, Walker, & Correa-De-Araujo, 2015; Merten, Pomeranz, King, Moorhouse, & Wynn, 2015; National Council on Disability, 2009). Additionally, due to the nature of their disability individuals with IDD are more likely to poorly manage chronic

conditions and to also have co-occurring mental health problems (Centers for Disease Control and Prevention, 2009).

Adults with IDD do not experience the same life expectancy as the general U.S. adult population. However, the move toward more community-based supports and services and increasing self-determination has meant that life expectancies for individuals with IDD have been increasing over time (Coppus, 2013; Factor, Heller, & Janicki, 2012; Thomas & Barnes, 2010). There has been a shift in the prioritization of services and supports for adults with IDD from institutional to home and community based services (HCBS) following the Supreme Court's *Olmstead* decision in 1999 (O'Keefe et al., 2010; Shogren, Wehmeyer, Reese, & O'Hara, 2006). In *Olmstead v. L.C.*, the U.S. Supreme Court ruled that individuals with disabilities should be provided community-based services over institutional based care (O'Keefe et al., 2010). The move to more integrated community living and work programs has created more consumer choice and enhanced self-determination for adults with IDD (Ticha et al., 2012; Wehmeyer & Bolding, 2001). Self-determination for adults with IDD has had many positive effects including improving quality of life and increased satisfaction with services and supports (Head & Conroy, 2005; Heller, Miller, & Hsieh, 1999).

While some adults with IDD experience full independence, the majority still need the support of a family caregiver and this is likely to continue due to more community-based care and long wait-lists for out-of-home care (Braddock et al., 2015; Heller & Schindler, 2009). There has been an almost four-fold increase in the number of people with IDD living with family members between 2000 and 2011, resulting in family caregivers providing the majority of daily support (Kaye, Harrington, & LaPlante, 2010; Larson, Ryan, Salmi, Smith, & Wuorio, 2012). A shortage of both living options and availability of support staff means the reliance on family

caregivers is likely to continue (National Council on Disability, 2013). Family support services are designed to benefit the family unit, with the ultimate goal to benefit the individuals with IDD and benefit families by reducing stress, reducing out-of-pocket spending to provide care in the home, allowing family members to maintain employment, and reducing the likelihood for institutional placement (Hecht & Reynolds, 2012).

In addition to the support of family caregivers, adults with IDD can also access formal supports and services. Medicaid is the primary funding source for formal supports and services for adults with disabilities. This group has the highest spending per capita of any Medicaid group, comprising 15% of all beneficiaries but spending 42% of all Medicaid dollars (Connolly & Paradise, 2012). Medicaid covers a broad range of services including traditional medical services and long-term services and supports (LTSS). It was estimated that in 2008, 41% of Medicaid spending for individuals with disabilities was for LTSS (Connolly & Paradise, 2012). Long-term services and supports are primarily provided through Medicaid Home and Community-Based Services (HCBS) Waiver programs include services such as personal care services, habilitation, supported employment, supported living, assistive technology, and family support (Braddock et. al., 2015). Medicaid LTSS costs rose from \$93 billion in 2002 to \$125 billion in 2011 and are anticipated to continue increasing due to the longer life expectancies of individuals with IDD and the aging U.S. population (Braddock et al., 2015; Centers for Medicare and Medicaid Services, 2013d).

The continued growth in Medicaid LTSS spending has resulted in more states exploring cost-savings mechanisms. Many are moving their Medicaid LTSS programs into a managed care model, referred to as Medicaid managed long-term services and supports (MLTSS) (President's Committee for People with Intellectual Disabilities, 2012; Saucier, Kasten, Burwell, & Gold,

2012). Managed care holds promise to control costs while improving quality of care (Gifford, Smith, Snipes, & Paradise, 2011). States have more experience with managed care for behavioral health and health care services, but adults with IDD had been excluded in most states until recent years due to their array of complex needs (Centers for Medicare and Medicaid Services, 2013a).

The evidence that exists about managed care for people with disabilities is mixed and is also limited to a primary focus on health care services rather than LTSS (Burns, 2009b; Duggan & Hayford, 2013). One study found a less access to specialists for Managed Care Organization (MCO) enrollees versus fee-for-service and no difference in monthly costs for those in fee-for-service counties or managed care counties (Burns, 2009a). Adults with disabilities in urban areas experienced better access to care under managed care policies compared to adults with disabilities living in rural areas (Coughlin, Long, & Graves, 2008). There is some evidence of reduced average annual preventable hospitalization rates by 25% for adults with disabilities in managed care and documented cost reductions from managed care have been primarily due to decreases in inpatient care and pharmacy costs (Bindman, Chattopadhyay, Osmond, Huen, & Baccetti, 2004). Another evaluation revealed cost savings for individuals with physical disabilities and aging adults, but did not find cost savings for adults with IDD in managed care (APS Healthcare Inc., 2005).

While there is some information about the influence of managed care on health care costs and utilization, very little is known about the influence of MLTSS. One reason for the limited information is due to the small proportion of LTSS provided under managed care, only six percent in 2012 (Eiken et al., 2014). The limited scope of information on individuals with IDD enrolled in MLTSS can be attributed to the small proportion of people with IDD enrolled in MLTSS, approximately 10% or 135,000 people in 2012 (Saucier et al., 2012). Another reason

for lack of consensus on MLTSS is the great diversity in MLTSS programs (Connolly & Paradise, 2012). States vary in their design and implementation of MLTSS programs including their financial and corporate structure, geographic reach, type of enrollment, level of stakeholder engagement, and scope of services (National Council on Disability, 2013; Saucier et al., 2012). This variability makes it difficult to draw conclusions about MLTSS's influence on costs and quality of care for adults with IDD.

Despite limited and mixed evidence about outcomes from MLTSS, the number of states implementing MLTSS for adults with IDD in recent years has expanded rapidly (National Association of States United for Aging and Disabilities, 2015; Saucier et al., 2012). Overall, the growth of MLTSS doubled from eight states in 2004 to 16 states in 2012 (Saucier et al., 2012). This growth resulted in a 269% increase in enrollees of MLTSS programs. In 2012, only seven states (AZ, DE, HI, MI, NC, PA, WI) included individuals with IDD in MLTSS. However, between 2012 and the time of the current study, six additional states (FL, IL, KS, NJ, NY, TX) transitioned to MLTSS, and it is projected that another four states (LA, NE, NH, TN) will make the transition in the near future (National Association of States United for Aging and Disabilities, 2015; Saucier et al., 2012).

Lack of information on the effectiveness of MLTSS and the growing trend to move more individuals with IDD into MLTSS is of concern to disability advocates. The primary concerns are that MLTSS will lead to decreased access to services and decreased consumer choice (President's Committee for People with Intellectual Disabilities, 2012). In addition, there are uncertainties about the application of the medical model of providing health services to non-medical LTSS, the state's ability to oversee the programs, the MCO's potential lack of knowledge and expertise about individuals with IDD, and complicated rate setting (President's

Committee for People with Intellectual Disabilities, 2012). The potential benefits of moving to MLTSS are improving care coordination, moving more people into community-based care instead of institutional care, reducing wait lists and unmet needs, and reinvesting savings to create new benefits (President's Committee for People with Intellectual Disabilities, 2012).

In response to the growing trend for states to provide MLTSS for individuals with IDD, advocacy groups, administrative agencies, and other experts in evaluation of Medicaid services have recommended best practices for designing and implementing MLTSS programs. The Centers for Medicare and Medicaid Services proposed new regulations in May 2015 covering MLTSS, currently out for public comment, which include these best practices (Centers for Medicare and Medicaid Services, 2015). In planning for MLTSS, careful consideration needs to be taken to ensure that the range of supports and services provided are both integrated and comprehensive with the integration of LTSS, behavioral health services, and health care services, even if they are financed through different mechanisms (Consortium for Citizens with Disabilities, 2012; Dembner, 2012; National Council on Disability, 2013). Managed care organizations (MCOs) need to offer a broad range of LTSS that include access to durable medical equipment, assistive technology to promote community living, and supported employment (Consortium for Citizens with Disabilities, 2012; Dembner, 2012; National Council on Disability, 2013). The MCO's provider network needs to include qualified LTSS, health, and mental health providers ensuring consumer choice and allowing for continuity of care during the transition to MLTSS (Centers for Medicare and Medicaid Services, 2013a; Consortium for Citizens with Disabilities, 2012; Dembner, 2012; National Council on Disability, 2013).

Given the reliance on family caregivers, MLTSS programs need to be responsive to the needs of both the individuals with IDD and their family caregiver(s) so the caregiver(s) can

continue to support and advocate for the individuals with IDD (Dembner, 2012; National Council on Disability, 2013). The Consortium for Citizens with Disabilities (2012) additionally recommends payment to family members as support providers. MCOs need to be prepared with alternative provider payment options available to consumers who choose non-agency based providers (Kaye, 2014).

Planning for the transition to MLTSS is a critical component. States proposing a move to MLTSS need to plan for long implementation timelines in order to allow for consultation with stakeholders including individuals with IDD, families, providers, and advocacy groups (Centers for Medicare and Medicaid Services, 2013a; Summer, 2011). These long planning timelines will help the state create a smooth transition process (Centers for Medicare and Medicaid Services, 2013a). Providers with expertise in IDD need to be involved in the design of MLTSS (National Council on Disability, 2013). A readiness assessment is recommended to evaluate the state's capacity and the MCO's capacity to handle diverse populations. After the readiness assessment is completed and the state has determined the MLTSS transition is feasible, then the implementation needs to take place in a phase-in approach rather than all at once. At the state level, it is recommended that MLTSS policies should include a requirement for states to develop a strategic plan with long-term goals from implementing MLTSS (National Council on Disability, 2013).

Stakeholder engagement is a pivotal aspect of MLTSS programs and needs to occur throughout planning, implementation, and evaluation (Truven Health Analytics, 2013). A formal process needs to be in place for ongoing stakeholder engagement and education both prior to and after implementation (Centers for Medicare and Medicaid Services, 2013a). It is particularly

valuable to engage providers with expertise in services and supports for individuals with IDD during program design and implementation (National Council on Disability, 2013).

Community living, avoiding discrimination, and consumer choice are values that must be reflected in MLTSS (Centers for Medicare and Medicaid Services, 2013a; National Council on Disability, 2013). The transition to MLTSS is not just about improving health and wellness, but also about promoting inclusion and independence of individuals with IDD (National Council on Disability, 2013). In order to avoid discriminatory practices, compliance with civil rights means that services and supports need to be cognitively and physically accessible for individuals with IDD so they are assured choice and availability of community supports (Centers for Medicare and Medicaid Services, 2013a; Consortium for Citizens with Disabilities, 2012; National Council on Disability, 2013). Services need to be provided in a person-centered approach in which the individuals with IDD decides on their goals and manages their services and supports (Consortium for Citizens with Disabilities, 2012).

Specific recommendations about participant enrollment and rights to file grievances provide important protections for individuals with IDD. If states make enrollment into MLTSS mandatory, then consumers must be assured choice between a minimum of two plans (Dembner, 2012). Once people are seeking services, states' policies should promote a single point-of-entry for MLTSS enrollment (Kaye, 2014). Clear procedures need to be in place for consumer oversight and protection including the ability to file a grievance and access to a fair hearing with continuation of services during an appeal (Consortium for Citizens with Disabilities, 2012; Dembner, 2012; National Council on Disability, 2013).

Truven Health Analytics (2013) proposed specific timeline tasks in the development of a MLTSS program from planning, implementation, through evaluation. Specific tasks in the first

(planning) phase involve engaging stakeholders, developing a communications plan, sharing program goals, consulting with the Centers for Medicare and Medicaid Services (CMS), assessing operational capacity, and creating a work plan. In order to implement MLTSS, a state must obtain legislative and CMS approval. Once approval is received, the implementation of MLTSS involves phasing in operational resources, selecting contractors and third party vendors, educating and informing providers, completing readiness reviews, and enrollment. Finally, once the program is operational, early experiences in the new MLTSS system need to be reviewed and the MLTSS system needs to be continually monitored in order to make corrections (Truven Health Analytics, 2013).

Study Purpose

In order to encourage a successful transition for adults with IDD and their family caregivers into MLTSS, best practice recommendations include guidelines for the planning and implementation of MLTSS. Given the level of uncertainty about MLTSS for adults with IDD and the continued expansion of MLTSS in the states, opportunities exist to further explore the experience of implementing MLTSS for adults with IDD to inform both policy and practice.

Each state has flexibility in the design of their MLTSS program, including its geographic scope, enrollment options, MCO corporate structure, nature of stakeholder engagement, and scope of services (National Council on Disability, 2013; Saucier et al., 2012). This complexity would make it difficult to make conclusions about MLTSS across states (Connolly & Paradise, 2012). Therefore, the study's overall objective was to describe the current implementation of MLTSS for adults with IDD and their family caregivers in Kansas.

Kansas was selected in consultation with national experts in the field of IDD policy due to the uniqueness of their approach to MLTSS compared to other states to date. The National

Council on Disability (2014b) has referred to Kansas as a “bellwether” on MLTSS for the IDD community. Their approach to MLTSS for people with IDD has never been done before, and it is possible that other states may attempt a similar process based on how the Kansas program fares. Kansas was the first state to utilize private for-profit MCOs, implement MLTSS statewide, require mandatory enrollment, and be fully inclusive across health, behavioral health, and LTSS for the IDD community (National Council on Disability, 2014b).

In 2011, Governor Brownback commissioned a working group to explore options for reforming the Kansas Medicaid program (KanCare, 2014). The workgroup, led by Lt. Governor Coyler, found the Kansas Medicaid program had experienced an annual growth rate of 7.4% since the year 2000 and they projected this growth would continue and increase given the changing demographics of Kansas (Kansas Medicaid Workgroup, 2011). Individuals with disabilities accounted for 49% of the growth in Medicaid spending from 2005-2010. Total Medicaid spending for individuals with disabilities was \$1,148,766,601 in 2010, with 42% of the Medicaid spending dedicated to LTSS (Kansas Medicaid Workgroup, 2011).

The workgroup sought public comment on Medicaid reform and heard from over 1,700 Kansas residents (Deloitte, 2011). Kansas residents identified a desire for more community-based services, more integrated whole-person care, different models to access services, and services that preserve or create a path to independence (Deloitte, 2011). Based on public feedback, the workgroup proposed Medicaid reform in Kansas with a mission “to serve Kansans in need with a transformed, fiscally sustainable Medicaid program that provides high-quality, holistic care and promotes personal responsibility” (Kansas Medicaid Workgroup, 2011, p.1).

The Medicaid reform occurred through the submittal and approval of a Section 1115 Demonstration waiver to CMS, moving the Kansas Medicaid program into a managed care

model with the following goals: 1) integrate the coordination of physical health, behavioral health, and LTSS; 2) improve quality of care by incentivizing quality outcomes with MCOs; 3) control Medicaid costs; and 4) provide a model for other states for Medicaid payment and delivery system reforms (Centers for Medicare and Medicaid Services, 2013b). The demonstration intended to “leverage private sector innovation to achieve public goals” in order to save the state \$853 million over five years (Kansas Medicaid Workgroup, 2011, p. 4).

The reform included Kansas renaming their entire Medicaid program to “KanCare” (Kansas Department for Aging and Disability Services, 2013). In January 2012, the state submitted their concept paper to CMS for the managed care (Section 1115) demonstration waiver, and in May, 2012 announced plans to implement managed care under KanCare statewide starting January, 2013 (KanCare, 2014). In June, 2012, the state awarded contracts to three private for-profit MCOs to provide KanCare services: 1) Amerigroup; 2) Sunflower State Health Plan; and 3) United Healthcare Community Plan (Kansas Department for Aging and Disability Services, 2013). A complete timeline of the Kansas Medicaid reform process can be found in Table 1.

Table 1: KanCare Timeline

| Date | Event |
|---------------|--|
| January 2011 | Governor Brownback commissions Medicaid reform work group to be led by Lt. Governor Coyle |
| January 2012 | Kansas submits Section 1115 Waiver concept paper to CMS |
| February 2012 | Deadline for MCO bids for contracts |
| March 2012 | KanCare Advisory Council, Consumer and Specialized Issue (CSI), and Provider and Operational issues (POI) work groups established to provide ongoing insight and recommendations on KanCare implementation |
| April 2012 | Kansas submits Section 1115 Waiver application to CMS |
| May 2012 | Kansas announces plan to implement KanCare January 2013, seven months to complete consumer and provider education Section 1115 Waiver effective January 1, 2013- December 31, 2017 |

Table 1 Continued

| Date | Event |
|-------------------------|--|
| June 2012 | Contracts signed with three MCOs (Amerigroup; Sunflower State Health Plan; and United Healthcare Community Plan) MCO contracts include provisions for completing readiness reviews, adding value added services, and requirements to use existing providers |
| July- November 2012 | Kansas Department of Health & Environment (KDHE) & Kansas Department for Aging and Disability Services (KDADS) hold educational meetings around the state with consumers and providers |
| January 2013 | KanCare goes live (LTSS carved out for IDD community) Adults with IDD receive medical and dental through MCOs IDD voluntary pilot of MCOs providing LTSS begins |
| August 2013 | Kansas submits amendment to include LTSS for individuals with IDD in KanCare effective January, 2014 |
| December 2013 | National Council on Disability submits a letter to CMS asking them to postpone approval timeline for implementation of MLTSS for IDD community in Kansas |
| January 2014 | Kansas announces temporary delay of MLTSS implementation for individuals with IDD to address concerns |
| February 2014 | MLTSS for adults with IDD begins 8,500 individuals on the HCBS waiver must enroll in KanCare Individuals with IDD living in Intermediate Care Facilities for Individuals with Mental Retardation (ICF/MR) excluded |
| March 2014 | Letter sent to 3,762 adults with IDD on wait list (2,631 receive no services, 1,141 receive some services but waiting for additional needed services) Letter asks individuals with IDD to submit request for needed services Kansas legislator allotted \$3.6 million to address wait list issues until savings from KanCare can be reinvested |
| January - December 2014 | KDADS and KDHE outreach to consumers and providers about KanCare KanCare IDD Friends and Family Work Group assists with education/outreach efforts |

KanCare originally carved out LTSS for adults with IDD and first completed a demonstration project beginning January, 2013 for the IDD population (KanCare, 2014). Enrollment in the pilot was voluntary, and 550 individuals with IDD and 25 IDD service providers opted to engage in the MLTSS pilot (KanCare, 2014). The overall goals of the pilot included: 1) establish relationships between the three MCOs and the IDD community; 2) identify

best practices for services delivery; and 3) create an efficient billing system (KanCare, 2014).

The experience from the pilot led to: the MCOs creating IDD specific teams led by former employees of the Kansas IDD system; deciding to keep services delivery through the existing Community Developmental Disability Organizations (CDDOs) and their affiliated community service providers, and Targeted Case Managers; and establishing a billing system for LTSS (Kansas Department of Health and Environment, 2013).

Despite lessons learned from the pilot program, there were concerns about implementing MLTSS for adults with IDD in Kansas. The National Council on Disability (2014b) submitted a letter to CMS asking them to require Kansas to delay MLTSS implementation for an entire year citing the following changes and recommendations: 1) allowing more time for stakeholder engagement and the submittal of a stakeholder engagement plan; 2) developing demonstration implementation council to oversee the implementation; 3) rolling out the program regionally over time, allowing for insights and changes before implementing statewide; 4) requiring MCOs to have care coordinator case loads of one care coordinator per 40 members with IDD; 5) disapproving the Ombudsman program being employed by one of the state oversight agencies (KDADs); and 6) disapproving the carve out of Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/ID) residents.

Despite the National Council on Disability concerns, CMS did not delay the implementation of MLTSS for adults with IDD statewide in February 2014 (National Association of States United for Aging and Disabilities, 2014). Enrollment in MLTSS is mandatory for individuals with IDD in Kansas (National Association of States United for Aging and Disabilities, 2014). Each KanCare MCO is available for consumer choice statewide (Kansas Department for Aging and Disability Services, 2013). The MCOs offer the full range of services

from health care, behavioral health, pharmacy services, dental care, and LTSS (KanCare, 2014). The Substance Abuse and Mental Health Services Administration defines (2011) behavioral health as including the prevention and treatment of mental health conditions and substance abuse disorders. State oversight for the MLTSS implementation is provided jointly through KDHE and KDADS (KanCare, 2014). The MCOs must complete annual external quality reviews and make all service utilization, trends in enrollment, and grievances/appeals available to the state oversight agencies (KanCare, 2014).

The Kansas Department of Health and Environment (2013) included several guidelines in their MLTSS implementation under KanCare in attempts to ensure a smooth transition for individuals with IDD into KanCare. These are listed below:

- Individuals with IDD could keep their current LTSS providers on their service plan, including those out of network, for up to 180 days until a service plan is mutually agreed upon;
- Individuals with IDD could keep their existing Targeted Case Managers as long as they are employed by a CDDO or a CDDO contractor;
- Individuals with IDD using residential providers could access them for up to one year regardless of their MCO contract status;
- MCOs would comply with guidelines from the CDDO regarding service delivery;
- MCOs would contract with at least two providers in each county ensuring consumer choice;
- MCOs would make at least three contract offers to all available LTSS providers in the state;

- KDADS and KDHE would review the service planning process implemented by the MCOs in the first 180 days of 2014;
- KDADS would review and approve all plans of care for IDD HCBS in which there is a reduction, suspension, or termination of services;
- CDDOs would remain the single point of entry for all LTSS;
- Targeted Case Managers from CDDOs would complete the needs assessment and Care Coordinators from MCOs would complete the health risk assessment. The results of these assessments would be coordinated into an Integrated Service Plan which would include their person-centered support plan, plan of care, behavioral health, and physical health information.

Kansas included specific goals in the Section 1115 demonstration application to help guide the vision of the reform while allowing means to evaluate KanCare's effectiveness. Their main goals were to improve care coordination and access to care across physical health, behavioral health, and LTSS (Centers for Medicare and Medicaid Services, 2013b). The ultimate outcomes of improved coordination and access would be improved quality of care, improved health and wellness of beneficiaries, while also controlling Medicaid costs through programmatic efficiencies (Centers for Medicare and Medicaid Services, 2013b). In addition, it was their hope that if successful in achieving these goals, they could serve as a model for other states in the Medicaid reform efforts (Centers for Medicare and Medicaid Services, 2013b).

The uncertainty of MLTSS for adults with IDD (Kansas's unique approach with hopes to be a model for other states) and the timeline for the KanCare implementation made Kansas an ideal selection for the current research study. The study's overall purpose was to describe the current implementation of MLTSS for adults with IDD and their family caregivers in Kansas. The

specific research aims included the following: 1) To understand the rationale behind and what actually happened with MLTSS implementation for adults with IDD in Kansas; 2) To understand how service coordination providers and family caregivers perceived care coordination and access to services in MLTSS; and 3) To understand how family caregivers and their roles were recognized in MLTSS for adults with IDD in Kansas.

Review of Theory and Framework to Guide Study

The use of theory in research provides a mechanism to define concepts, the interaction between concepts, and propose propositions regarding the concepts to explain or predict a phenomenon (Glanz & Bishop, 2010). The unified theory of family quality of life (FQOL) was developed following a systematic review of existing IDD research and is designed to be a grand theory from which subsets of its constructs and propositions can be tested for their relationships (Zuna, Summers, Turnbull, Hu, & Xu, 2011). The unified theory of FQOL was designed to explain how system changes in policy and programs, like MLTSS, can ultimately influence individuals with IDD and their family caregivers (Zuna et al., 2011).

Compared to theories, frameworks can provide more structure to systematically design, implement, and evaluate programs (Green & Kreuter, 2005). The objective of the current study was to describe the implementation of MLTSS in Kansas. Accordingly, a broader systems level implementation framework can provide concepts or constructs found in the literature specific to managed care implementation or other policies associated with individuals with disabilities. The use of an accepted systems level policy implementation framework can also help with drawing comparisons across the MLTSS literature.

In order to identify systems level policy implementation frameworks specific to the disability field and/or managed care, a systematic literature review was completed using the

matrix method to guide the structure and process of the review (Garrard, 2011). The following key words were used to complete the review: policy implementation framework; disability; managed care; policy implementation; health policy; implementation; implementation framework; behavioral health; and managed care implementation. Key word searches in PubMed, Web of Science, PsychINFO, and EBSCOhost were completed for articles published in 1990 to the present. The year 1990 was selected to correspond with the timeline of the first MLTSS program for individuals with IDD initiated in Arizona in 1988 (National Council on Disability, 2013).

A total of 1,502 abstracts were reviewed and sixty-one articles were selected for full review. Twenty-six articles were found that discussed implementation frameworks. These 26 articles were further reviewed to identify if they were specific to the disability field and/or managed care, and for their potential fit to inform this study. Three articles included examples of potential systems level policy implementation frameworks specific to the disability field that could help guide this study (Hebbeler, Spiker, & Kahn, 2012; Kertroy et al., 2012; Laragy & Ottmann, 2011). All three articles obtained from the systematic literature review proposed or utilized Bronfenbrenner's (1979) ecological model to review implementation. Bronfenbrenner's (1979) model was used to describe the influence of policy changes on programs and services and to provide recommendations for implementation guidance in the disability field (Hebbeler et al., 2012; Laragy & Ottmann, 2011). Therefore, Bronfenbrenner's ecological model was applied in the current research study.

The unified theory of FQOL provided the justification for tracing the influence of policy changes on the individual with IDD, the family caregiver, and the family unit. Bronfenbrenner's ecological model provided a framework to discuss policy influence on program implementation.

To date, a systems level policy implementation framework specific to managed care could not be found. This study proposed the combined use of the unified theory of FQOL and Bronfenbrenner's ecological model to explore the implementation of MLTSS for adults with IDD and their family caregivers. This research study could potentially make theoretical and framework contributions to the literature by combining MLTSS best practices guidelines within a larger framework that includes the implementation experiences of MLTSS from the state/regional director, services coordination provider, and family caregiver perspectives. A brief overview of the unified theory of FQOL and Bronfenbrenner's ecological model will be provided and will be followed by their application to this research study.

Unified Theory of Family Quality of Life

In order to develop the unified theory of FQOL, Zuna et al. (2011) reviewed existing theory and peer-reviewed research on families which included a member with an IDD. The goal of the unified theory of FQOL was to make it dynamic and responsive to change so it can be used at the policy and practice level to evaluate and drive change. Zuna et al. (2011) define family quality of life as “a dynamic sense of well-being of the family, collectively and subjectively defined and informed by its members, in which individual and family-level needs interact” (p. 262). In the unified theory of FQOL (Zuna et al., 2011), FQOL is the outcome of individual and family unit characteristics and interactions, and specifically how the family and individual respond to receiving services and supports (see Figure 1) .

Zuna et al, (2011) describe three systemic factors that are proposed to indirectly influence FQOL: 1) systems (networks designed to meet society's needs, e.g.: health care system); 2) policies (guidelines and regulations); and 3) programs (groups providing the services). There are family level performance factors and individual level performance factors that interact in

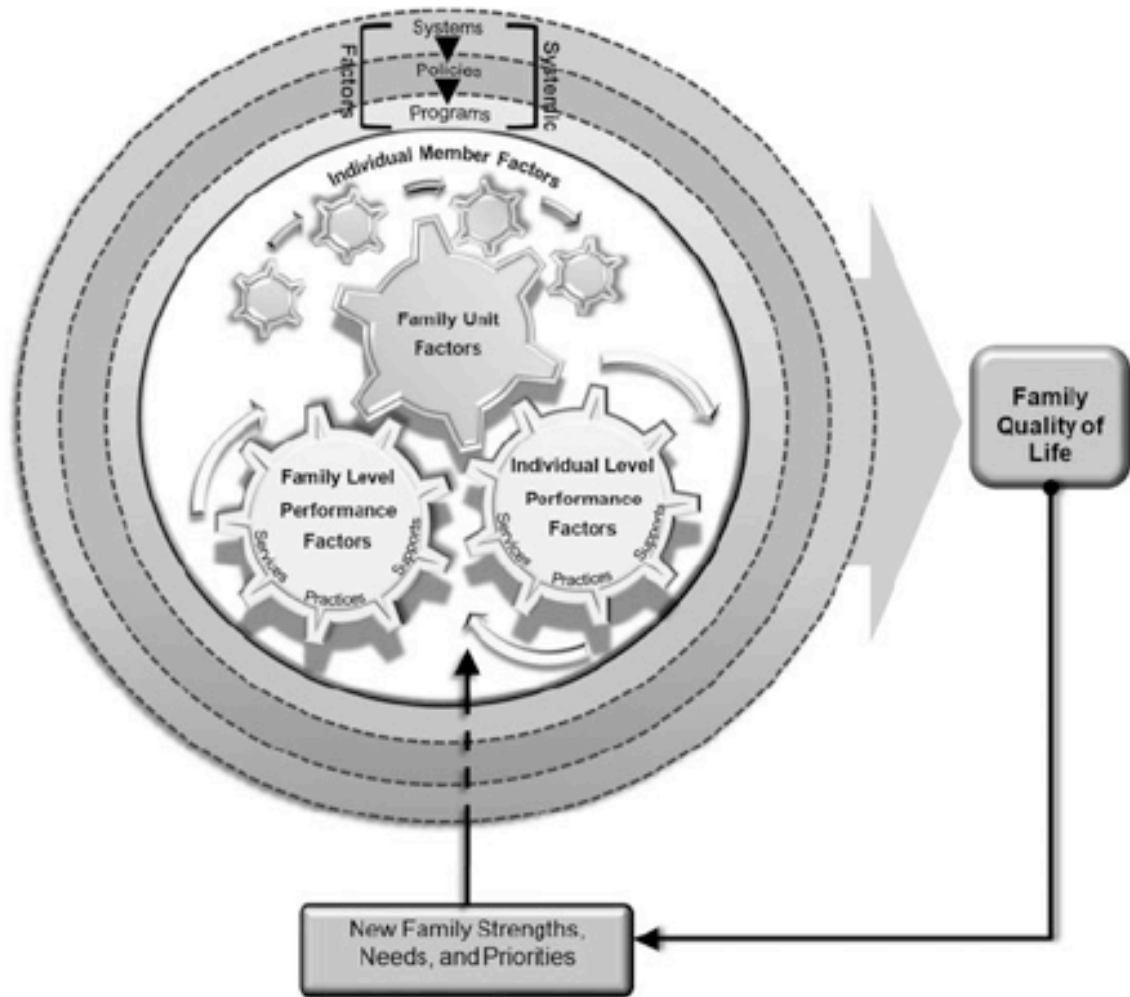


Figure 1: Unified Theory of FQOL

Enhancing the quality of life of people with intellectual disabilities, R. Kober (Ed.), 2011, pp. 241-278, Theorizing about family quality of life, value of a theory of family quality of life, Zuna, N., Summers, J.A., Turnbull, A.P., Hu, X., & Xu, S., Figure 15.4, original copyright notice is given to the publication in which the material was originally published, with kind permission from Springer Sciences and Business Media

response to the system level factors, changing to influence the family unit and ultimately to impact FQOL. As a family unit, the family has characteristics and group dynamics that are influenced by each individual member’s characteristics, beliefs, and demographics.

The performance factors at the family and individual unit levels are the services, supports, and practices delivered to the individual and to the family (Zuna et al., 2011). Services are the formal services provided and supports are not direct services, but more in-tangible offerings like education and information support. Practices are the procedures or processes

through which supports and services are delivered. The unified theory of FQOL posits that changes to systems, policies, and programs, have influence on performance factors (services, supports, and practices) which then influence family functioning, and ultimately FQOL (Zuna et al., 2011).

Bronfenbrenner's Ecological Model

Ecology refers to the relationship between individuals and their environments. Ecological models can be used to describe the interrelations between individuals and their social and physical environments (Stokols, 1992). Bronfenbrenner's ecological model (1979) explores human development as it relates to the different levels of analysis, referred to as the microsystem, mesosystem, exosystem, and macrosystem, see Figure 2.

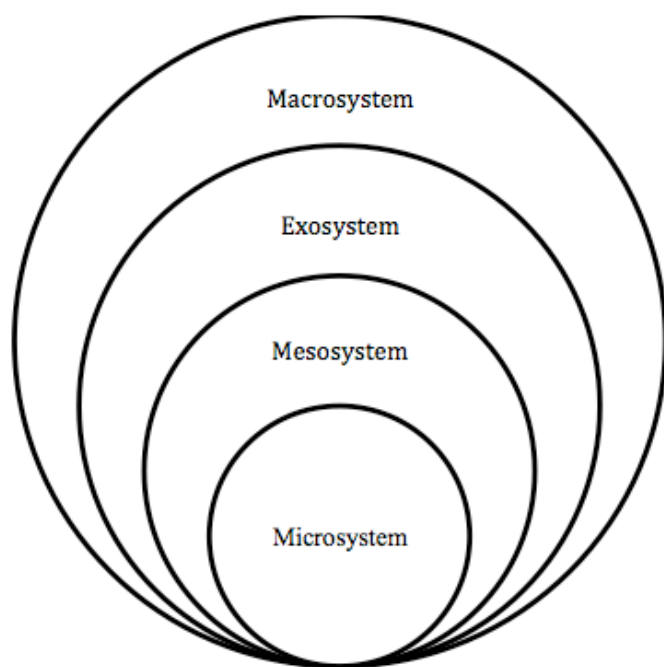


Figure 2: Bronfenbrenner's Ecological Model

The microsystem includes the individual's knowledge, skills, attitudes, and the individual's activities and experiences related to their close interpersonal relationships, for example, the individual with IDD and their family members (Bronfenbrenner, 1979). The mesosystem describes the relationship between two or more interacting settings the individual is involved with, for example, the

individual with IDD and their service coordination provider. The exosystem is the larger external and immediate environment that influences activities at the mesosystem directly. The individual

is not an active participant at the exosystem level, but activities at this level can influence or be influenced by the systems in which the individual plays an active role. Finally, the macrosystem is the broader philosophies and cultural views of the society that can influence the other levels (Bronfenbrenner, 1979).

Theory and Framework Application to Current Study

The research questions and overall objectives for this study will be discussed in light of the theory and framework. A summary of their application can be found in Table 2. The design of the interview protocols and the analysis of study data were also guided by the theory and framework.

Research Aim One

Research Aime One was to understand the rationale behind and what actually happened with MLTSS implementation for adults with IDD in Kansas. This aim was partially informed by existing literature regarding MLTSS in Kansas and further addressed through interviews with state/regional level representatives including IDD program directors, MCO representatives, and IDD advocacy groups. According to the literature, the rationale behind the move to MLTSS was to reduce costs while improving the quality of care (Gifford et al., 2011). The ultimate goal of MLTSS was to improve quality of care through increased access to and coordination of behavioral health, physical health, and long-term support services in order to improve health and wellness (National Council on Disability, 2013).

Schalock and Alonso (2002a) propose that any change to policy and to services and supports for individuals with IDD should only occur if the ultimate outcome is to improve quality of life. In the unified theory of FQOL, policy changes, like moving to MLTSS, would influence the structure of programs that influence the manner in which the performance factors (services

and supports) were provided to families. The services and supports received interact with the individual and family unit factors to ultimately influence FQOL. This study was designed to describe implementation experience and not produce conclusions about the ultimate outcomes of MLTSS, including FQOL. However, the unified theory of FQOL was still informative to highlight the critical role of family caregivers in MLTSS and how policy changes (for example, MLTSS) need to be responsive to their needs.

Table 2: Application of Theory and Framework in Current Study

| Unified Theory of FQOL | Bronfenbrenner's Ecological Model | Research Aim(s) | Application to MLTSS |
|---|-----------------------------------|-----------------|--|
| Systemic Factors (systems, policies, programs) | Macrosystem | 1 | Philosophy behind MLTSS Values from IDD field (consumer choice, civil rights, inclusion) Federal guidelines MLTSS best practices |
| Systemic Factors (systems, policies, programs) | Exosystem | 1, 2 | State MLTSS policies MCOs policies Interaction between MCOs, service coordination providers, and state government State level perspective |
| Individual and Family Level Performance Factors (services, practices, supports) | Mesosystem | 2 | Service coordination providers practices and procedures mandated by MCO Informal supports recognized in person-centered and family-centered planning process Services provided Interaction between MCO and service coordination provider Interaction between service coordination provider and family caregiver Service coordination provider perspective |
| Individual and Family Unit (beliefs, demographics) | Microsystem | 3 | Interactions among family members in relation to MLTSS Family caregiver role acknowledgement and perspective |

Additionally, Research Aim One was guided by concepts found in the ecological model's macrosystem and exosystem. The macrosystem can be interpreted as the underlying values of

and best practices for MLTSS described by the federal government and disability advocacy groups. Understanding these values should guide what the rationale behind MLTSS is and what actually happened. The overall goal driving the federal government's support of MLTSS is to reduce costs while improving quality of care in order to improve the health and wellness of care recipients (Gifford et al., 2011; National Council on Disability, 2013). Improved quality of care can be achieved through improved care coordination and access to services. However, for individuals with disabilities, the ultimate goal must not strictly be tied to physical health and behavioral health outcomes, but also to promoting community inclusion and independence (National Council on Disability, 2013).

Values at the macrosystem level for MLTSS that should to be reflected in MLTSS policy include community living, consumer choice, and civil rights (Centers for Medicare and Medicaid Services, 2013a). Funding for MLTSS programs should encourage access to the scope of services and supports required, encouraging community living and supports for family caregivers (Centers for Medicare and Medicaid Services, 2013a; National Council on Disability, 2013). Consumer choice is achieved through a broad provider network and a person-centered approach to decisions about services and supports (National Council on Disability, 2013). Civil rights are protected by MLTSS programs providing services and supports provided in compliance with the Americans with Disabilities Act, Rehabilitation Act, and the Olmstead v. L.C. decision, in order to avoid discriminatory practices (Centers for Medicare and Medicaid Services, 2013a; Consortium for Citizens with Disabilities, 2012; National Council on Disability, 2013). The guidance and values regarding best practices for MLTSS were reflected upon in state/regional level interviews and included in the codebook utilized in data analysis.

At the exosystem level, aim one explored realization of the philosophical goals behind MLTSS. In particular, the state/regional and provider perspective on policies and procedures promoting care coordination and access to services utilized by the MCOs. State policies that promoted best practices recommendations were also explored related to planning and stakeholder engagement.

Research Aim Two

Research Aim Two was to understand how service coordination providers and family caregivers perceived care coordination and access to services in MLTSS. At the individual level and family level in the unified theory of FQOL, there are performance factors that directly addressed this research aim (see Figure 3 and Figure 4).

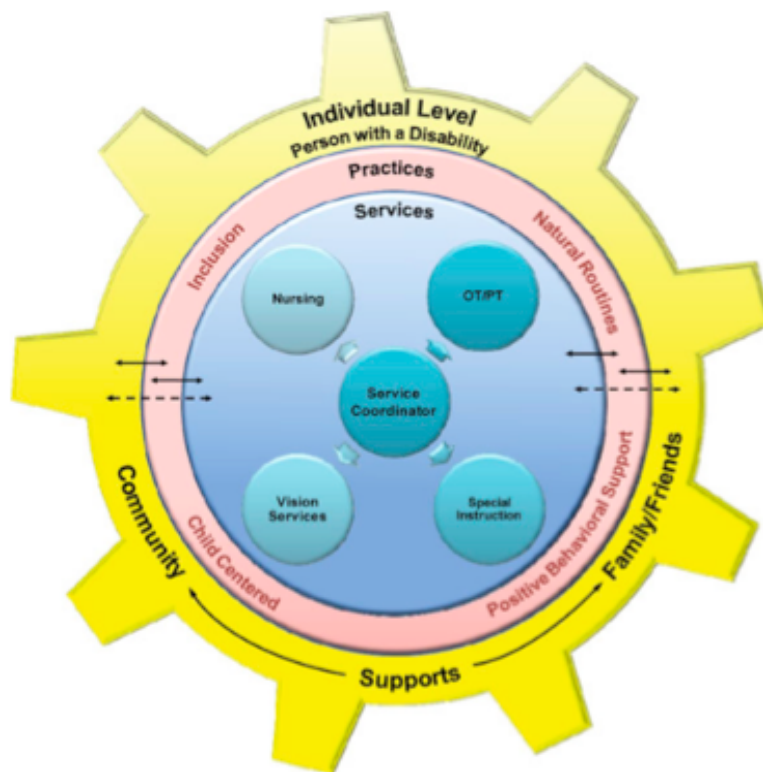


Figure 3: Individual Level Performance Factors
Enhancing the quality of life of people with intellectual disabilities, R. Kober (Ed.), 2011, pp. 241-278, Theorizing about family quality of life, value of a theory of family quality of life, Zuna, N., Summers, J.A., Turnbull, A.P., Hu, X., & Xu, S., Figure 15.2 original copyright notice is given to the publication in which the material was originally published, with kind permission from Springer Sciences and Business Media

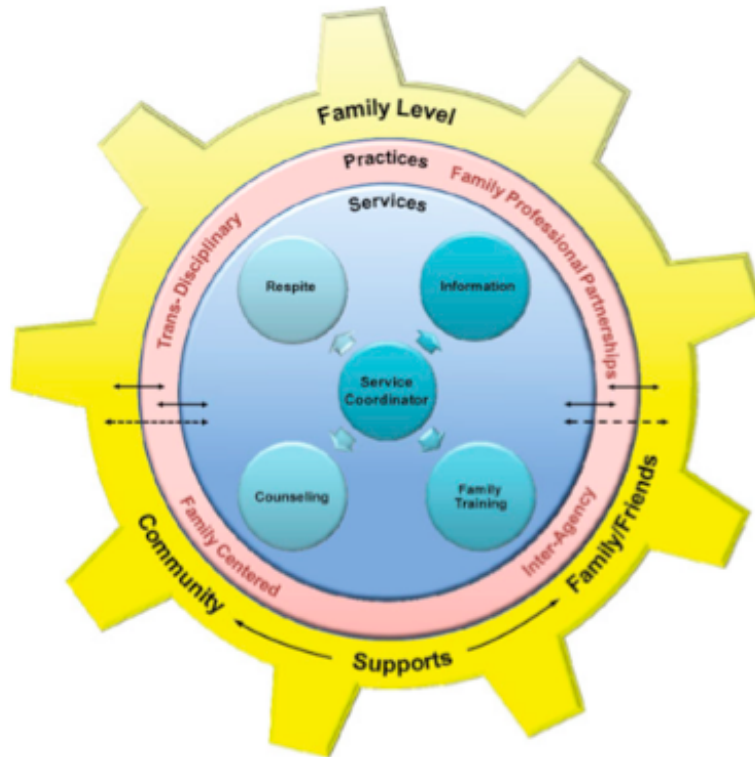


Figure 4: Family Level Performance Factors
Enhancing the quality of life of people with intellectual disabilities, R. Kober (Ed.), 2011, pp. 241-278, Theorizing about family quality of life, value of a theory of family quality of life, Zuna, N., Summers, J.A., Turnbull, A.P., Hu, X., & Xu, S., Figure 15.3 original copyright notice is given to the publication in which the material was originally published, with kind permission from Springer Sciences and Business Media

First, the “services” defined in this theory included the activities of the LTSS providers, the service coordination provider, and examples of typical services provided to families, such as respite and counseling, or to individuals, such as supported employment. These are the services the service coordination providers were asked to describe access to and coordination of in MLTSS. Second, “practices” are the procedures or processes through which services are delivered. In this case, the “practices” were the procedures mandated by the managed care organization (MCO), to include arranging for care coordination and access to services in a managed care model. Third, the unified theory of FQOL defines “supports” as the less formal resources received from interaction with the community at large.

The service coordination provider would need to evaluate the family and individual supports, as these can influence the types of formal services required in MLTSS. For example, a family with a great deal of help with caregiving from friends may not need as many hours of respite services as a family with fewer supports. The service coordination provider would also need to understand the characteristics, demographics, and beliefs of the individual with IDD and their family members in order to better plan for needed services. The service coordinator providers shared their experiences with services and supports implemented in the MLTSS practices model. These performance factors ultimately were influenced by policies at the state Medicaid office and/or the CMS who provided guidance to programs, like MCOs, to implement MLTSS.

Family caregiver perceptions of access to and coordination of services and supports in MLTSS were guided in a similar fashion as the service coordination provider perceptions using the unified theory of FQOL. The family caregivers discussed the family-level and individual-level performance factors of services received under MLTSS through interaction with their service coordination provider. The informal supports available to the family caregiver and individual would influence the types of services they would require and must coordinate with the service coordination provider. The practices, or the policies and procedures under MLTSS, would influence the mechanisms by which family caregivers advocated for needed services for the individual with IDD as well as for the family. Their family unit and individual member characteristics would also influence family caregiver perceptions regarding care coordination and access to services in MLTSS.

Additionally, research aim two was addressed at the two ecological levels: exosystem; and mesosystem. The exosystem included interaction between MCOs, LTSS provider agencies,

and the state government policies that influenced MLTSS implementation. The state was responsible for the oversight of the program to monitor quality which would be achieved through enhanced care coordination and access to services (Centers for Medicare and Medicaid Services, 2013a). Improved care coordination would be achieved through coordination between behavioral health, physical health, and service coordination providers. Policies need to also be in place to ensure access to a care coordinator with expertise across physical health, behavioral health, and LTSS fields or there should be access to a group of care coordinators with individual expertise working together (National Council on Disability, 2013).

Access to services should be achieved by providing funding support for all needed services, and supports including durable medical equipment, assistive technology, and supported employment to promote community inclusion (Centers for Medicare and Medicaid Services, 2013a; Consortium for Citizens with Disabilities, 2012; National Council on Disability, 2013). Enhancing provider networks by supporting personnel development in agencies for a stable workforce and providing funding for a variety of provider options should facilitate consumer choice and access to services (Centers for Medicare and Medicaid Services, 2013a). These guidelines were incorporated into the service coordination provider interview protocol and were used to help frame the analysis.

At the mesosystem level, the service coordination provider's perceptions of care coordination and access to services in MLTSS were explored based on interactions with the individual with IDD and their family caregiver. The service coordination provider should be supported by their agency and the MCO to encourage community living and inclusion and consumer choice in their assessment and care coordination decisions (National Council on Disability, 2013). The service coordination provider should see coordination between behavioral

health, physical health, and LTSS agencies reflected in their process to help individuals with IDD and their families access services. There should also be a mechanism in place that service coordination providers are aware of and share with families regarding individuals with IDD rights to file grievances and have a fair hearing if they are not satisfied with provided supports and services (Centers for Medicare and Medicaid Services, 2013a). Civil rights will also be protected if providers were given support to provide information and services that are cognitively and physically accessible to individuals with IDD (National Council on Disability, 2013).

Family caregivers discussed their perceptions of care coordination specific to the level of coordination across agencies and the type of care coordination assistance they are provided. If MLTSS is being implemented as planned to ensure access to services, then family caregivers should identify how consumer choice, community living, and civil rights are reflected in their relationships with providers at the mesosystem level.

Research Aim Three

Research Aim Three was to understand how family caregivers and their roles were recognized in MLTSS for adults with IDD in Kansas. According to the family unit performance level in the unified theory of FQOL, information from family caregivers and service coordination providers could provide insight into the manner in which care coordination was occurring, specifically, whether the care coordination process was taking on a person-centered approach, family-centered approach, or a combined approach. The person-centered planning approach involves the individual with IDD identifying priorities and goals and the supports and services needed to achieve these goals. While in a family-centered approach, the goals of the individual with IDD are honored while also addressing the needs of their family caregiver (National Council on Disability, 2013).

Additionally, Research Aim Three was further explored at the microsystem level where family caregivers described how their roles were acknowledged in MLTSS. Specifically how decision making related to services and supports included support services designed to meet their needs, while also respecting the choices of the individual with IDD. Family caregivers could discuss their roles and responsibilities within the family unit and how their roles influenced changes to supports and services in MLTSS.

The results of the current study, in light of the unified theory of FQOL and Bronfenbrenner's ecological model, will be reviewed in Section IV.

Manuscript Introduction

This study's overall purpose was to describe the current implementation of MLTSS for adults with IDD and their family caregivers in Kansas. The results of the study will be presented in two separate manuscripts found in Sections II and III.

Manuscript One (found in Section II), *Implementation of Medicaid Managed Long-Term Services and Supports for Adults with Intellectual and/or Developmental Disabilities in Kansas*, explored Aims One and Two of the study: 1) To understand the rationale behind and what has actually happened with MLTSS for adults with IDD in Kansas; and 2) To understand how service coordination providers and family caregivers perceived care coordination and access to services for adults with IDD in MLTSS.

Manuscript Two (found in Section III), *Family Caregivers as Needed Partners: Recognizing Their Role in Medicaid Managed Long-Term Services and Supports*, explored Aim Three of this study: To understand how family caregivers, and their roles, were recognized in MLTSS for adults with IDD.

SECTION II: MANUSCRIPT ONE
Title Page and Journal Selection

Manuscript One Title: Implementation of Medicaid Managed Long-Term Services and Supports for Adults with Intellectual and/or Developmental Disabilities in Kansas

Primary journal Selection: *Intellectual and Developmental Disabilities*

Reason for journal selection: The American Association on Intellectual and Developmental Disabilities publishes this journal and the target audience includes researchers, clinicians, students, policy makers, and professionals in the IDD field. This journal was selected given its applied focus to inform policy and practice for the IDD field. Complete journal guidelines can be found at: <http://www.aaidjournals.org/page/authors/idd>

Secondary journal selection: *Journal of Policy and Practice in Intellectual Disabilities*

Abstract

Many adults with intellectual and/or developmental disabilities (IDD) can access health and long-term services and supports (LTSS) through Medicaid. States are reforming their Medicaid LTSS programs from a fee-for-service model to a Medicaid managed LTSS (MLTSS) approach hoping to improve quality of care and reduce costs, although there is limited evidence of MLTSS effectiveness. This study's objective was to contribute to the research base by describing MLTSS implementation in Kansas for adults with IDD. In-depth semi-structured interviews were completed with 31 stakeholders representing state/regional involvement, service coordination providers, and family caregivers. Findings identify the importance of adequate planning, stakeholder engagement, and provider network adequacy in light of difficulties experienced with care coordination and accessing services.

Introduction

Adults with intellectual and/or developmental disabilities (IDD) in the United States are experiencing longer life expectancies in part due to the shift towards more community-based services and supports and the promotion of self-determination (Factor et al., 2012; Thomas & Barnes, 2010). Despite these gains, adults with IDD still experience health disparities with higher rates of chronic conditions, comorbid mental health conditions, and lower rates of preventative care than the general U.S. adult population (Croen et al., 2014; Krahn et al., 2015; Merten et al., 2015). The health disparities experienced by adults with IDD are resulting in an increased focus on ways to improve access to care and care coordination to promote better health and wellness (Krahn et al., 2015).

Currently, the complex needs of adults with IDD are primarily met through the support of family caregivers and Medicaid funded long-term services and supports (LTSS). Medicaid is the

primary funding source for health care services and LTSS for adults with IDD (Braddock et al., 2015). There has been nearly a four fold increase in the number of adults with IDD living with a family caregiver and approximately 71% of individuals with IDD require the support of a family caregiver (Braddock et al., 2015; Larson et al., 2012). It is anticipated that Medicaid spending for LTSS will continue to increase due to longer life expectancies of people with IDD and the aging of the U.S. population (President's Committee for People with Intellectual Disabilities, 2012; Saucier et al., 2012). The need to address the complex needs of adults with IDD and their family caregivers, while also attempting to control Medicaid LTSS spending, is resulting in more states reforming their Medicaid LTSS programs (Saucier et al., 2012).

Managed care is one mechanism many states are utilizing (or considering to utilize) in reforming their Medicaid LTSS system (Saucier et al., 2012). Managed care has been used for decades to address cost and quality concerns for health and behavioral health services. However, the use of managed care for LTSS, called Medicaid managed long-term services and supports (MLTSS), is a newer phenomenon (National Council on Disability, 2013). The existing evidence regarding managed care for individuals with disabilities is primarily focused on health care services, and the evidence of managed care's ability to control costs while improving quality of care is mixed (Bindman et al., 2004; Burns, 2009a, 2009b; Caswell & Long, 2015; Coughlin et al., 2008; Duggan & Hayford, 2013; Lewin Group, 2009; Premo, Kailes, Schwier, & Richards, 2003; Wegman et al., 2015). The transition to MLTSS from traditional fee-for-service reimbursement for adults with IDD is a growing trend; seven states utilized MLTSS for adults with IDD in 2012, six states implemented between 2013 to the present, and four additional states are planning to transition to MLTSS in the next few years (National Association of States United for Aging and Disabilities, 2015; Saucier et al., 2012).

The trend of states transitioning from fee-for-service LTSS to MLTSS for adults with IDD is of concern for those in the disability field. The primary concern regarding MLTSS is that it could result in reduced access to care, decreased consumer choice, and less individualization of services and supports, contributing to existing disparities experienced by individuals with IDD (President's Committee for People with Intellectual Disabilities, 2012). However, managed care also holds promise to address health disparities if it can successfully improve coordination of care across health, behavioral health, and LTSS (National Council on Disability, 2013; President's Committee for People with Intellectual Disabilities, 2012). The move to MLTSS can also result in transitioning more individuals into community-based care while using system efficiencies to address unmet needs through the expansion of service offerings and the reduction of wait lists (President's Committee for People with Intellectual Disabilities, 2012).

The potential promises in light of the concerns regarding MLTSS, combined with general uncertainty from existing evidence, has resulted in advocacy groups, administrative agencies, and those with Medicaid expertise producing best practice recommendations for MLTSS planning, implementation, and evaluation (Centers for Medicare and Medicaid Services, 2013a; Consortium for Citizens with Disabilities, 2012; Dembner, 2012; National Council on Disability, 2013; Truven Health Analytics, 2013). The best practices recommendations are intended to help states transition successfully to MLTSS while continuing to meet the needs of adults with IDD and their family caregivers. Recently, the Centers for Medicare and Medicaid Services (2015) produced proposed regulations, currently under review, to address Medicaid managed care, which reflect best practices recommendations.

As MLTSS grows across the U.S., there are opportunities to further explore the experience of implementing MLTSS to inform both policy and practice in light of best practices

recommendations. Each state has flexibility in the design of their MLTSS program including its geographic scope, enrollment options, managed care organization (MCO) corporate structure, nature of stakeholder engagement, and scope of services (National Council on Disability, 2013; Saucier et al., 2012). A study reviewing experiences with MLTSS for adults with IDD in four states confirmed the diverse experiences of stakeholders with MLTSS (Williamson et al., under review). Unique characteristics of each state's program can make it difficult to draw conclusions about MLTSS across states, resulting in the current study's focus on MLTSS implementation in one state (Connolly & Paradise, 2012).

Among states which have recently transitioned to MLTSS for adults with IDD, Kansas has been referred to as a 'bellwether state' given their unique approach (National Council on Disability, 2014b). The Kansas MLTSS program, titled KanCare, was the first MLTSS program for adults with IDD to utilize three private-for-profit managed care organizations (MCOs) and to integrate across the full spectrum of services including health, behavioral health, and LTSS (KanCare, 2014). Individuals with IDD began receiving health and behavioral health services in 2013 through KanCare and full integration, including LTSS, began February, 2014 (KanCare, 2014). Stated goals of KanCare are to improve access to services and better coordinate care for all Medicaid recipients (Centers for Medicare and Medicaid Services, 2013b). Initial evaluations of the KanCare implementation across all disability groups identified difficulties not only with access to providers and prescription medications, but also confusion regarding the care coordination process (Hall, Kurth, Chapman, & Shireman, 2015).

The unique approach to MLTSS for adults with IDD utilized in KanCare coupled with evidence of initial challenges faced in providing better access and care coordination make it an ideal time to further reflect on the experiences of stakeholders in Kansas. In addition, the

proposed CMS Medicaid managed care regulations also identify best practices for implementation, which can be assessed in light of lessons learned from the KanCare implementation to date. Therefore, this study's purpose was to describe the current implementation of MLTSS for adults with IDD and their family caregivers in Kansas. This manuscript reports partial results of a larger qualitative case study. The specific research aims discussed in this manuscript are the following: 1) To understand the rationale behind, and what actually happened, with MLTSS for adults with IDD in Kansas; and 2) To understand how service coordination providers and family caregivers perceived care coordination and access to services in MLTSS.

Methods

A case study approach was utilized in this research study since it is a method recommended for policy implementation studies and for research concerning managed care (Gold, 1999; Kaskutas, Schmidt, Weisner, & Greenfield, 2000). A particular strength of the case study approach is it does not assume that programs or policies have a predictable path in their implementation, so it is open to discovering new information about implementation (Balbach, 1999). In addition, a case study methodology allows for in-depth inquiry of a current phenomenon in a real-world context and is a preferred methodology when there is minimal or no control of events by researchers (Yin, 2014). Case studies are intended to discuss and analyze a bounded system. For the purpose of this study, the bounded system or case was Kansas, a state implementing MLTSS for adults with IDD (Creswell & Maietta, 2002).

After receiving approval from the University of South Florida Institutional Review Board, recruitment of participants began in January, 2015. Three different stakeholder groups were recruited to participate in the study to triangulate understanding (Yin, 2014). Participants

who represented statewide or regional groups (Group One) involved in MLTSS for adults with IDD and service coordination providers (Group Two) working directly with families were recruited through direct email contact followed up with a mailed invitation to participate. Family caregivers (Group Three) were recruited through advocacy groups and provider groups who distributed a study flyer via mail and email. Snowball sampling was also used in which families could share the researcher's contact information with other family caregivers they thought might want to share their KanCare experience. Family caregivers were provided a \$15 Walmart gift card for their time. Inclusion criteria for family caregivers were being the primary caregiver of an adult with IDD (over age 22), still residing in the family home and utilized KanCare.

In-depth semi-structured telephone interviews were completed with participants between February, 2015 and June, 2015. Interview protocols were specific to each group to accurately capture differing perspectives, and were pilot tested with individuals with expertise in MLTSS and IDD. The protocols included questions regarding experiences with the transition into KanCare, access to services, and care coordination. The lead researcher conducted all interviews, and participants provided verbal consent for participating in the study. All interviews were audio recorded. A total of 31 interviews were completed, ranging in length from 25 minutes to an hour. Thirteen of the interviews were statewide or regional group representatives (Group One), seven of the interviews were service coordination providers (Group Two), and eleven interviews were family caregivers (Group Three) of adults with IDD.

Data analysis was guided by the framework method, which is designed for qualitative research relevant to policy and health services research (Pope, Ziebland, & Mays, 2000). The framework method is comprised of seven stages: 1) transcription of interviews; 2) familiarization with the interview data through reviewing transcripts; 3) coding the transcripts; 4) developing a

working analytic framework; 5) applying the analytic framework; 6) charting the transcribed data into the framework matrix; and 7) interpreting the data by reviewing the framework matrices (Gale, Heath, Cameron, Rashid, & Redwood, 2013). Framework matrices were structured with each row representing a participant and each column a new code from the study's codebook. An *a priori* codebook was developed based on CMS's MLTSS best practices including the larger themes of planning, stakeholder engagement, state oversight, consumer education, care coordination, and access to services. The codebook was updated as interviews were being reviewed for final application across all interview transcriptions. The analyses were completed using the qualitative software NVivo 10 (QSR International, 2014). Preliminary results were shared with all participants for member checking to confirm accuracy prior to analysis and producing the final study results for dissemination.

Findings

Research Aim One

Aim One was developed to understand the rationale behind and what actually happened with MLTSS implementation for adults with IDD in Kansas. Participants described what they perceived to be the goals or rationale behind the move to KanCare. A main goal discussed was controlling or reducing costs coupled with concerns of how this would be possible without cutting services.

All along, they said, 'No services will be cut'... You can't save money without cutting services or cutting rates. I mean, it doesn't compute in my checkbook. I don't know how they can do that. (State/Regional-05)

MLTSS also held promise to increase access through expanding the provider network, to provide new types of services, to promote preventive health care, and to integrate care.

We definitely have gaps in different types of services for people with IDD in Kansas; home and community-based services in some of the more rural parts of the state are lacking. We have gaps in parts of the state where we don't have enough dentists who are willing to support people with IDD, physicians willing to support people with IDD...the ability to have contracts with all of these providers and help develop their willingness, their ability, and capacity to work with people with IDD. (State/Regional-13)

People will be seeing their primary care physicians, that they're not consistently seeking only emergency medical treatment, making sure that preventive screening and things like that are getting done. (State/Regional-11)

I think that primary goals are to better integrate care. Prior to KanCare, no individual entity for the person had the complete picture of what services and supports the person needed. (State/Regional-13)

The following findings review how participants experienced implementation to date and their reflections on the potential to achieve goals related to better access to services and more integrated care.

Transition Experience

Participants expressed feelings of confusion and fears regarding services being cut and Targeted Case Managers losing their jobs at the time of the transition.

Now if you need something, you have to go to your managed care company. So there's someone standing in between you and your benefits, and that can be confusing for a person with an intellectual disability. It's getting confusing for their family members and caregivers, their natural supports, who help them.

(State/Regional-12)

It was confusing because we heard lots of stuff in the media. We were getting bombarded with lots of different information and it was explained different ways so it wasn't really that clear. (Family-06)

I think a lot of the Targeted Case Managers expected to be losing their jobs and services are going to be cut. (Provider-07)

Initial impressions of the transition to KanCare were that it made the system feel more complex and less transparent.

The levels of people we have to go through are different with each MCO. Each one does their own thing and it's very difficult to keep up with three different companies doing it. (Provider-04)

There's no transparency. There's no ability for the people that are guardians to be able to look up and see, this is who I can call if I have a question about that.

(Family-01)

We had a system that you could look at and watch for trends and you could see how many people were being served, how much money it costs all that kind of stuff, but as soon as we implemented the managed care, all of that became one big pile of money, and there's no way to really track what's going on.

(State/Regional-01)

Participants also discussed their views on the knowledge and experience of the MCOs regarding individuals with IDD. It was positively received that the MCOs had hired people with experience from the IDD field.

Each insurance company, managed care organization has within their organization someone who specifically is a liaison with the IDD community...they're hiring people who are right on, who have the right philosophy. (State/Regional-09)

Despite hiring people from the IDD field, the MCOs have experienced a learning curve regarding managed LTSS for IDD. Therefore, there have been some challenges with their policies and procedures fitting the needs of the IDD population. This included integrating LTSS into a traditional medical model approach as well as understanding the diverse needs of the IDD population.

They (MCOs) were pretty good at fixing broken legs and putting stiches in, but the thought of something that has to be flexible enough to take into account the changing needs of people with disabilities as they age, as they have different kinds of health concerns. I think all of that was a real steep learning curve for the MCOs. (State/Regional-04)

Sometimes they [families] talk to someone in claims. You'll hear some of the comments that have been made and the people that just really don't understand the IDD population and the questions they're asking. (Provider-07)

When I called KanCare for information, they said, 'Well, you're not authorized for us to give you any information.' I said, 'I'm his legal guardian.' 'Well, you're going to have to send this and this' ... And I said, 'No, I'm not. I've already done this through the state. If you want legal documents, you contact the state. That's who you're contracted with not me.' (Family-04)

The MCOs were able to provide additional resources to impact systems change in Kansas. The MCOs spear-headed efforts and offered grant funding for initiatives focused on addressing law enforcement and employment initiatives for people with IDD. Additionally, the MCOs provided new health care resources, which were important for people with IDD who often have complex medical needs.

A lot of the MCO staff do come from such a medical model, but it's also been kind of a good thing because a lot of the people that we serve do have pretty complex medical needs. (State/Regional-10)

While it is too soon to see if the goals of KanCare have been realized, there have been some challenges and successes, that are important for other states to learn from as they consider an MLTSS program. Managed care organizations can provide a great deal of resources, but they may need more training into the specific needs of the IDD population as well as to the provision of LTSS outside of a medical model approach. Study participants identified stakeholder engagement and longer planning timelines as mechanisms through which this could be accomplished.

Stakeholder Engagement and Planning

Stakeholders in KanCare included the state, MCOs, providers, individuals with IDD and their families. Stakeholder engagement opportunities were provided during the planning and implementation of KanCare. Participants identified stakeholder engagement as a meaningful way to understand where gaps exist, what resources were needed, and ways to alleviate fears.

I think knowing in advance from the state's perspective and from stakeholder perspective what can be improved upon is really key as well and where resources are needed. (State/Regional-13)

It was important in allowing people to ask questions and to help alleviate a lot of their fears they had about managed care. (State/Regional-11)

However, participants did not always identify stakeholder engagement attempts as successful, either because stakeholder issues weren't resolved, stakeholder questions weren't answered, or they weren't sure what happened to the stakeholder input.

There were a lot of meetings. Opportunities to provide input, but we don't feel like anything was done with that input. (State/Regional-05)

I think that in those meetings they answered questions, but they also evaded the real point to some of these questions and it just wasn't balanced. (Family-03)

You would try to assist them in the development of things that they need to look at.

The only answer that we would get is, 'We'll look at it and we'll get back to you,' and they never did. (Provider-01)

In addition to more meaningful stakeholder engagement, longer planning timelines could have allowed time to address feedback from stakeholders, to prepare staff, and to reduce stress among families.

They've tried to compartmentalize different challenges they knew they're going to face and had dedicated workgroups... the problem is that all happened so fast... groups were able to give some important and useful feedback that probably helped eliminate or avoid some pitfalls that might have otherwise not been avoided, but it just went too fast. (State/Regional-10)

I think that there was just so much mass confusion... I think that they tried hard and I think that their system of implementation was there, but they needed more time. (Provider-01)

They were rushed to get it done and they implemented it too soon without thinking about how is this going to affect the people that have services now. (Family-01)

According to participants, timelines for planning and piloting KanCare were far too short, making it difficult to utilize results and apply changes in the implementation.

Research Aim Two

Research Aim Two sought to understand how service coordination providers and family caregivers perceived care coordination and access to services in MLTSS.

Care Coordination

Under KanCare, individuals with IDD and their family caregivers are to work with both their existing Targeted Case Manager (TCM) and a Care Coordinator (CC) from their designated MCO to coordinate their LTSS, behavioral health, and medical services. Initially there was confusion over the roles of each team member.

To date, it still doesn't seem like the Care Coordinators know exactly what their role is going to be. (Provider-01)

Continued access to TCMs was reported as important given their long-term relationship with families and the apprehension regarding the role of the CCs. Families interpreted the CC as another layer of bureaucracy, an overseer of the TCM, and were uncertain of what the CC could really do to assist them.

Our Targeted Case Manager is probably the only way that we have survived these last few years with KanCare. (Family-02)

It was a little frustrating in that suddenly what everything that the Targeted Case Manager usually did for us, and really in effect still does for us, was doubled.

(Family-08)

I don't think that the Care Coordinator can really do anything so I don't call her.

(Family-05)

It was reported that the TCMs primarily took the lead in scheduling all meetings with the families and often the TCMs worked to help resolve issues for families with the MCOs. Periodically, the time spent by TCMs resolving issues was unpaid.

They have a customer care line... It's an 800 number that sends you through just an onslaught of different people and waiting and waiting and waiting. TCMs can't bill for their time and sit on hold for half an hour trying to get through this customer care line if the Care Coordinator can't help them. (Provider-01)

Despite the critical role of the TCM, some participants reported that it was difficult to get approved for additional TCM hours when families needed more case management support. The evaluation process was a team effort including both the TCM and the CC. Figure 5 provides an overview of evaluations completed by individuals with IDD and their family caregivers in order to access and coordinate services in KanCare. The main changes in the initial evaluation process with the move to KanCare involved having the MCO CC present at meetings to complete their new Health Risk Assessment (HRA) and the Integrated Service Plan (ISP). There was confusion, as the HRA seemed to overlap with the existing BASIS assessment used to determine eligibility for services. Additionally, the HRA did not always address needs specific to individuals with IDD.

Care Coordinator Knowledge and Experience. Given their affiliation with large MCOs, CCs could provide access to new resources and new solutions to problems that TCMs previously did not have access to. In some cases, CC's were specialists in behavior management or they were medical professions who could assist with complex needs. Care Coordinators were also tasked with looking at all aspects of care for a more integrated approach.

We consider the medical aspect of it too... before it was all separate and now we can look at a person's health issues along with their IDD waiver issues and make a more integrated impact that way. (Provider-05)

Participants reported that some CCs were hired from the field, which helped establish trust in those cases. Even those with experience in IDD didn't necessarily yet know how to navigate the new system.

The Care Coordinators don't necessarily know how to trudge through all the red tape in the system that the MCOs have set up... they try to help but they don't exactly know how to help them through their own organization's system.

(Provider-01)

Care Coordinator Caseloads and Turnover. While CCs could be a great resource to the support team, participants also identified that CCs have difficulty finding time for families given their large caseloads. Some CCs provide specialized services and have a smaller caseload of 80 families, whereas those without a specialization can serve up to 140 families, or even more. Targeted Case Managers, on the other hand, typically carry caseloads of 30 families or less allowing them more contact hours with families. Targeted Case Managers report monthly contacts (in-person or phone) with families at a minimum and CCs report requiring in-person contact twice a year minimally. The large CC caseloads also made it difficult for them to get to know individuals with IDD and their families.

To be honest, if you have 100 or 120 people on your caseload as a Care Coordinator, how do you know what their specific needs are? (Provider-01)

Large caseloads carried by CCs may have also contributed to families not identifying with what the CC could provide them and to CC turnover reported by families.

We've only really only met the Care Coordinator once, and that was when they did the assessment. We have a new one now. (Family-05)

Given the large CC caseloads and the existing relationship TCMs had with families, it was not surprising that a collaborative relationship between the CC and the TCM was identified as being necessary to coordinate services. Families still primarily identified with their TCM as a point of contact, given their limited exposure to their CC.

Access to Services

All three MCOs in KanCare were tasked with providing members a comprehensive package of services and supports including health care, behavioral health, and LTSS. Participants discussed provider network adequacy and federal and state oversight activities, which influenced access. Consumer choice was primarily focused on choice of the MCO. Access to services will be reviewed by service areas discussed by participants, which include: 1) behavioral management; 2) crisis/exception requests; 3) durable medical equipment; 4) health care; 5) LTSS; and 6) value added services (includes dental care). In addition, some key issues related to urban versus rural residency were also discussed as they relate to accessing services.

Provider Network. A primary means to ensure access to services in MLTSS is to ensure the adequacy of the provider network available to individuals with IDD and their family caregivers. The MCOs were required to offer contracts to all existing providers, but providers could opt in or opt out of KanCare, resulting in some families having to find new providers.

We had to find a new doctor, and that was difficult. The KanCare people sent us this big catalog of listed physicians. So I just started down the list and I kept

getting, 'No we're not taking any new patients. No we don't take KanCare.'

(Family-05)

The state instituted a continuity of care time period for individuals with IDD in KanCare as maintaining existing providers was critical to individuals with IDD and their families, whom often worked years to put together a team of resources.

We had built a resource group... and it was tough because sometimes the community isn't aware of how to help a person with special needs. So it's a long process to even establish a list of resources that you can rely on. (Family-02)

Efforts to expand the provider network were not without challenges given the existing gaps in provider availability prior to KanCare. Providers were not always willing to work with individuals with more complex needs.

The reality is that providers can pick and choose based on what that person's need is and whether or not they think they can actually provide that person the service. (Provider-03)

Participants reported difficulty with billing processes including expectations to provide un-billable services, denied payments, delayed approvals, and inaccurate payments.

Federal and State Oversight. Federal and state oversight activities also influenced access to services for individuals with IDD in KanCare. As part of the approval for the demonstration waiver to operate KanCare, CMS mandated that the state and the MCOs address the underserved

waitlist. The underserved waitlist included individuals eligible for services on the waiver, but only receiving a portion of their approved services. Advocacy groups had been working to eliminate the underserved waitlist (approximately 1,700 people) for years, but with the advent of KanCare, CMS required the MCOs to provide all requested services to the underserved waitlist members.

The state also included provisions that any proposed reductions or changes in LTSS by MCOs for an individual with IDD must be reviewed by the state. The MCOs must continue to offer the same level of LTSS until the state has approved or denied the request.

MCOs have to submit [to the state] more than just a reduction, even if it's just converting their services from in-home support to day services... if the person requested additional services, but the MCO denied any portion of the request, those all go to the state portal. (Provider-07)

Consumer Choice. In order to ensure consumer choice of MCO providers, individuals and families need to receive education regarding MCO plans and options. Families discussed going to in-person education sessions and also getting informational mailings. Some families felt they got adequate education while others were left with more questions.

Families were auto-assigned to an MCO unless they made another selection. Families had the option of changing MCOs within 90 days of auto-assignment or to wait to change during next open enrollment. Choosing an MCO was complicated for some families given the complex needs of their loved one and provider listings not always being up to date. Some of the families auto-assigned chose to change MCOs because their primary physician wasn't on the plan or due to

access issues with their medications. In cases where the family selected the MCO, it was based on the availability of their providers whom they trusted.

I changed a couple of months ago, because I live in a small town and don't have access to large chain pharmacies and the MCO was no longer going to pay for his prescription through the local pharmacy. (Family-04)

I picked it based on the trust that her doctors were in this plan. She has a neurologist that I don't want to change from, and she has her general practice doctor that I don't want to change from ever. (Family-06)

Behavioral Management and Crisis/Exception Requests. One service noted as more readily available to Kansans after KanCare was additional behavioral management support. These were provided either through specialized MCO CCs or as part of value added services that MCOs offered in which families could access a team of specialists for consultative services.

Prior to KanCare, if an individual with IDD in Kansas was on the waiting list and was in some form of crisis situation requiring immediate access to services, a crisis/exception request would be submitted. If the crisis/exception request was approved, then the individual would be taken off the wait list and granted access to needed services and supports. After implementation of KanCare, participants reported these crisis determinations were taking much longer to obtain, leaving some members in emergency situations.

People are in crisis. They are in crisis now... we have had an individual that the mother has gone to the nursing home and her son went to the nursing home with her because there was nothing else available. They had to pay out of pocket and they didn't really have the money to do that, but they didn't have anything else to do. (State/Regional-05)

Durable Medical Equipment. Families experienced difficulty receiving needed durable medical equipment (DME) in KanCare, due, in part, to billing systems not having the appropriate billing codes for all parts required for DME, especially wheelchairs. Since DME providers were having difficulty getting reimbursement, they were delaying providing the DME and were expecting families to pay up front.

She was obviously probably causing herself some headaches and was crying a lot and when she gets upset she gets even more self-injuries. So, we went to the doctor and she said she needs a helmet. I went. Got measured. Everything was ready. Unfortunately, when it came to the resource provider, they called and said, 'Okay, it's here but you'll need to bring the... I think it's like \$300.00.' They said, 'But you'll have to pay upfront.' I said, 'Excuse me?' I said, 'You're kidding, right?' They said, 'No. You have MCO right?' I said, 'Yes.' They said simply, 'I'm sorry. We just can't wait on them. They don't pay.' (Family-02)

Health Care. Participants reported some physicians refusing to work with KanCare but families were relieved when they got to keep their existing physicians. Some families were frustrated with inaccurate information regarding physician affiliations with MCOs.

Health care-wise, that stayed relatively the same. Yes. Once we got him on the program with his primary care doctor, everything pretty much calmed down in that arena. (Family-01)

I called a bunch of people and they said the provider book is just not up-to-date. All I know is that my son's provider is on there now and he can go to the local emergency room if he needed it. (Family-07)

Long-term Services and Supports. In order to ensure continuity of care with the transition to KanCare, the state of Kansas required that any reductions or changes to LTSS proposed by the MCOs would require state review and approval. This ongoing review was extended through the end of calendar year 2015. Additionally, maintaining the role of TCMs in care coordination for LTSS eased the transition into KanCare.

Families participating in this study had mixed experiences with LTSS access. Some individuals saw no changes in actual services and supports received despite any anxiety they experienced with the process. Other families had to go through the appeals process while some were offered new services, but in both experiences there were challenges in acquiring workers to provide the approved services.

They give you the service; the opportunity to have it, but finding somebody to provide service is a different story... finding somebody who could provide that service, who can fit their plan, what their description of that provider should be is a different story. (Family-06)

Providers discussed more service options and increased flexibility to request additional services.

If anything, we have more families, I think, asking for additional services. So in that sense, we have not really done reductions, it's more additional services, but being cautious of, 'is it a need versus a want?' (Provider-06)

The only reductions in services discussed were related to situations in which families had not been utilizing all of their allotted hours. In some cases, there were changes in types of supports being presented to families in order to encourage community living or to explore residential living outside of living in the family home.

I think the scope is a little larger as far as finding out what other opportunities there are... It's not automatically a group home. You have other options and so we're able to explore those options a little bit better. (Provider-05)

One of the quality goals for the MCOs to achieve under KanCare was to increase the number of people with IDD successfully gaining competitive employment in Kansas. The MCOs invested in grant programs to reform employment opportunities for Kansans with IDD. Participants identified challenges with the existing KanCare employment options including difficulty finding competitive employment for individuals with more complex support needs. Providers identified promoting competitive employment over sheltered workshops for participants. However, providers also discussed difficulty accessing supported employment services in a timely manner for individuals with IDD.

When we did the switch over, with one company they dragged their feet on a guy that I had working and needed supported employment. . . . By the time that they finally gave most of what we were asking for he had already gotten fired, because he didn't have someone coming in to help him deal with the stuff. (Provider-03)

Value Added Services. All three MCOs offered what are referred to as “value added services” in KanCare for individuals with IDD. These value added services were services that Medicaid had not previously covered in Kansas. Dental services were a value added service that proved difficult to access. The few dentists that were available were located in urban areas making it difficult for families to access them from rural areas. Due to few providers, there were also long wait lists for these dental services.

The other thing that they will do is pay for one or two dental cleanings a year and that's been very helpful but the big problem is trying to find a dentist that accepts the KanCare. My son had to be sedated, even to have his teeth cleaned... You have to go to this one particular dental facility...it takes months.So my son does not get his teeth cleaned every six months. It's just once a year. (Family-05)

The MCOs also offered health promotion and preventive services like smoking cessation, chronic disease management, and Weight Watchers®. However, there were challenges to accessing some of these services in rural areas and also some families didn't want preventive care guidance from the MCOs.

I'm not interested in having the calls come... 'You need to take her blood sugar and it's got to be between this and that. We're going to check back and see how you're doing.' 'You know what? I'm managing it. We're fine.' It was getting a little annoying. (Family-06)

The MCOs also offered what are called “practice visits” where an individual with IDD could practice what it would be like to visit an OB-GYN or a dentist. These visits were intended to reduce their anxiety about seeking out preventive health care, however these were not utilized as expected.

Another value added benefit was offering hospital stay support so support staff could get paid to accompany an individual with IDD while they were in the hospital. Hospital stay support had been utilized but it was difficult to get those providers paid.

It is basically paying the provider to have support staff with someone when they were hospitalized ...we have some people utilizing that and having a really hard time in the end getting paid for it. (State/Regional-06)

Respite was also included as a value added service and was being utilized but not as frequently as expected. Finally, the MCOs offered debit cards or gift cards that individuals could earn cash rewards for completing preventive health behaviors. Families reported issues with these cards including not understanding how to utilize them, the limited number of stores where they could be used, and difficulty using them to buy needed items.

Well, now actually, the MCO did send me a debit card that could be used for certain types of things that I use in caring for him. So I took it to the pharmacy to purchase these disposable bathing cloths for when he's sick and I can't bathe him. I stood in line at the register and all these people lined up behind me and it took the gal 10 minutes and then she finally came back and she said, 'I'm sorry, you can't have this without a prescription because this is Medicaid...well, what's the point?' (Family-10)

Rural Versus Urban. In general, families residing in more rural areas had difficulty accessing providers, as the provider networks were often limited in rural areas. At times, families living in rural areas decided to become the paid supports provider since they couldn't find reliable personal attendant care staff.

A lot of families have family that provide care because they are in a rural area that it's hard to keep somebody on when they've got to drive 30 minutes to get there because they live out in the country somewhere. ...by the time they drive it and everything, they're getting less than minimum wage. (Provider-02)

Experiences with access to services varied greatly depending on the type of service and also were difficult to access for those residing in rural areas. It will be important for KanCare to continue to work on expanding the provider network and resolve provider payment concerns in order to ensure consumer access and choice.

Discussion

Lessons learned from the implementation of KanCare to date can provide important guidance to other states considering MLTSS for adults with IDD. Table 3 is a summary of the 10 best practice recommendations for implementing MLTSS programs from CMS compared with lessons learned provided by study participants. Study participants identified six out of these 10 best practices as important.

Overall, participants shared feelings of confusion and fear coupled with a sense of increased complexity and reduced transparency in KanCare. However, they also noted that some of these difficulties likely could have been alleviated if there had been longer planning timelines and more meaningful stakeholder engagement efforts. Stakeholder engagement efforts could have proved more meaningful if stakeholders could identify how their feedback contributed to system changes. There are not current adequacy standards for stakeholder engagement in MLTSS, but one mechanism identified could involve states providing travel funding support or small stipends to stakeholders to improve sustainability of engagement efforts (National Council on Disability, 2014a).

Effective care coordination holds promise to better integrate care and improve access to services, but there were difficulties with identifying roles of care coordination team members in KanCare. Ongoing access to existing Targeted Case Management services prior to MLTSS implementation was critical, as caseloads for MCO Care Coordinators were at times too large for them to have adequate time to spend getting to know families and addressing their needs. In a recent review of existing processes for implementing care coordination in MLTSS, Saucier and Burwell (2015) identified great variability in care coordinator case loads and roles across states. It has been proposed that states at a minimum need to identify the care coordinator qualifications,

caseload sizes, and expectations for frequency of contacts with individuals and their families in MLTSS (Saucier & Burwell, 2015). The National Council on Disability (2014a) identified a recommended caseload of one Care Coordinator for every 40 members with IDD in MLTSS.

Achieving access to services in MLTSS will not be realized without developing an adequate provider network by increasing capacity of providers to work with adults with IDD and extending services to rural areas. It was of benefit to be able to offer dental services in KanCare, but these services were not accessible given the limited scope of available providers. The Office of Inspector General (2014) evaluated access to primary care providers and specialists in managed care in 32 states. Over half were not offering appointments for managed care enrollees. Improving provider capacity will also make care more accessible to address ongoing health disparities faced by individuals with IDD (Krahn et al., 2015; United Nations, 2006). A provider network with adequately available providers will also allow for consumer choice that can result in higher consumer satisfaction (McDonnell & Graham, 2015). Accessible consumer education efforts are also needed to ensure consumers are making informed choices (Peterson & Hyer, 2015).

Efforts made by MCOs to staff their programs with those having expertise in IDD was important, but the policies and procedures guiding MLTSS were not entirely adapted to accurately reflect specific needs of the IDD population. Continuity of care provisions and ongoing state oversight were important to minimize any disruptions in receiving needed LTSS. The MCOs were able to provide additional services, but timely and accurate provider payments will be important to ensure access to services.

There are limitations to this study potentially helpful to guide future research efforts. The current study reviewed the experience of one state and took a cross-sectional view of

implementation. Future research could explore additional state experiences while also completing more longitudinal follow-up with participants to identify common issues across states and to capture experiences after the initial transition. If a state completes a roll out implementation of MLTSS, expanding the program by county or regional basis, then future research could compare the experiences with care coordination and access to services in MLTSS areas versus fee-for-service areas. Participation bias is also a concern, as those who chose not to participate in the current study could have very different implementation experiences. However, results of this study can inform future survey efforts of MLTSS programs.

A key strength of this research is the study timing during a rapid expansion of MLTSS across states. Results of this study can be used to inform future MLTSS policy and practice decisions nationwide. It can be challenging to make state-specific Medicaid research relevant to policy makers due to vast differences in approaches to MLTSS available to states (Gold, 1999). However, new CMS (2015) managed care regulations are promoting a more standardized approach and results from this study support key aspects of the new regulations. Ideally, this study would be able to take a longitudinal approach and follow up with participants over time to reflect on goals realized in MLTSS. Despite this challenge, participants' responses could help inform future evaluation efforts of newly implemented MLTSS programs.

This study has implications for research, practice, and policy. Continued growth in MLTSS, with lack of standardized evaluation processes to evaluate quality, means that areas for future research could explore designing evaluation instruments reflective of these best practices (Kaye & Harrington, 2015). While there are emerging practice models for care coordination in managed care, no standard approach has been proposed and more evaluation is needed to identify effective care coordination approaches (Saucier & Burwell, 2015). In order to ensure

access to services, provider network adequacy development efforts should be identified and strategies to enhance provider capacity shared. Identifying successful stakeholder engagement strategies for future MLTSS planning, implementation, and evaluation is needed. Finally, the upcoming changes to CMS MLTSS regulations that reflect the best practices identified in this study (see Table 3) will be important for other states to review when developing MLTSS policy.

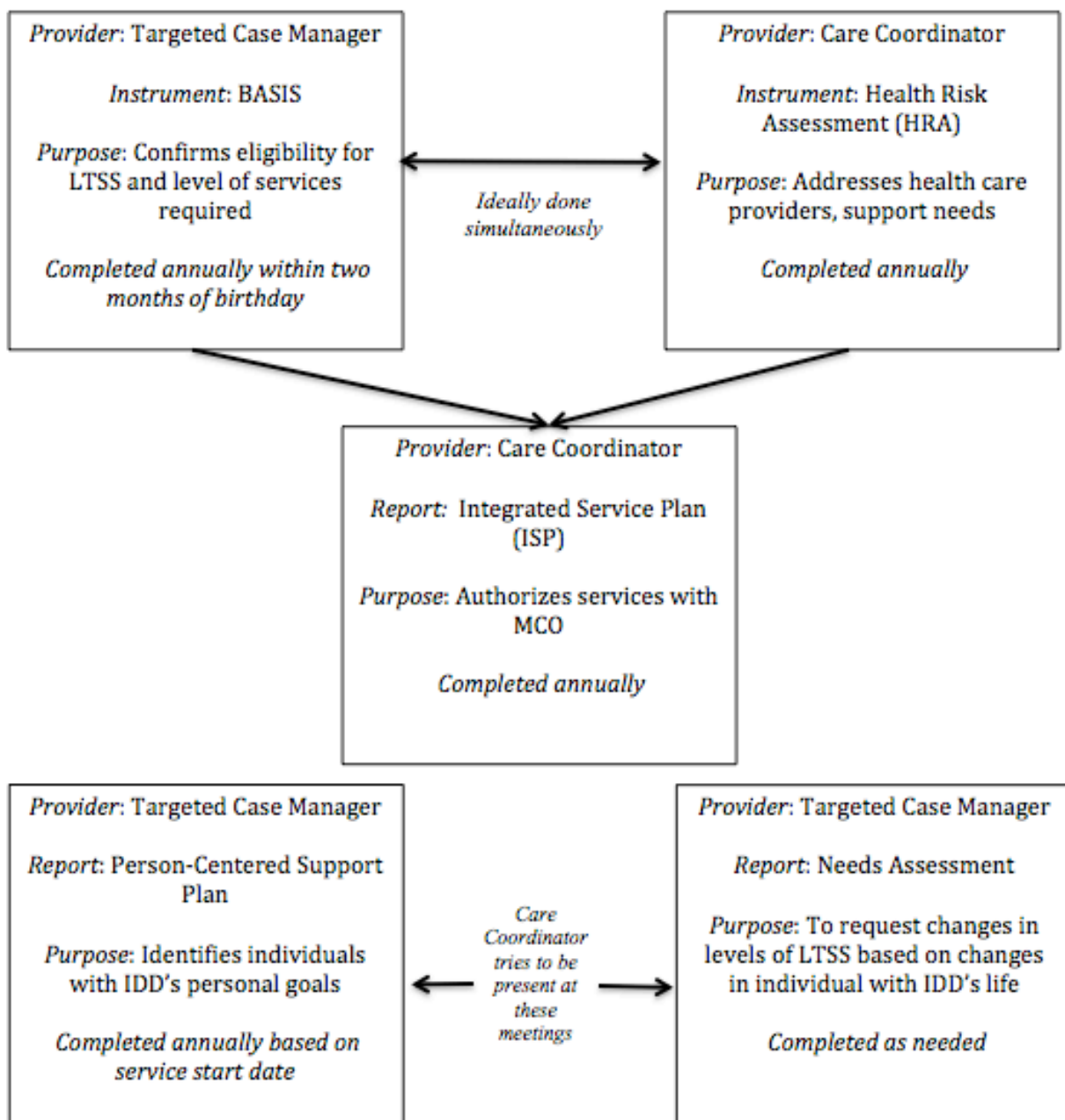


Figure 5: Evaluation Process Completed by Service Coordination Providers

Table 3: CMS Proposed Rule and Study Lessons Learned

| CMS Regulations: 10 Best Practices for Implementation of MLTSS | Study Lessons Learned |
|---|--|
| 1) Adequate planning for ensuring a smoother transition. | <p>Take time in the planning phases to learn from the current system. Understanding how the current system works will help the new system fill any gaps and also ease the transition process. This would also provide for mechanism to compare operations before and after MLTSS implementation</p> <p><i>Do you understand the way that the system works now? Who drives that system? Those are two things that you really need to understand as you are rolling it in...how to work with the system, the existing system. All of the big battles were really not about the services themselves but more about how to fit managed care into the existing system. (State/Regional-11)</i></p> <p><i>Then also maybe having a survey ahead of time about where the gaps are... What does the provider network look like and where has the state experienced gaps in care? ...So the managed care companies know in advance where can you have the most impact and where are the priority areas that you need to start. (State/Regional-13)</i></p> <p>Use a phased-in approach to implementation. This would allow time to learn from experiences and to adapt the system prior to full implementation and also would limit disruption of the current system.</p> <p><i>If you've been in fee-for-service since Medicaid began to provide services for long-term care, then you really need to take a phased in approach to rolling it out. ...Roll it out and see what issues come up, deal with those, work out the kinks, and then you can roll out more counties. (State/Regional-02)</i></p> |

Table 3 Continued

| CMS Regulations: 10 Best Practices for Implementation of MLTSS | Study Lessons Learned |
|--|---|
| 1) Adequate planning for ensuring a smoother transition. <i>Continued.</i> | <p>Allow for adequate time to plan the program and complete a meaningful pilot of the program before going live. The pilot should test how the system will work including billing, care coordination, and access to services. The planning time could also include more training for MCO providers so they can learn from the current system.</p> <p><i>The planning process is to me the most important process. So that to me is the foundation and probably what sticks out to my mind the most as to what I would've changed. The devil's in the details. (State/Regional-02)</i></p> <p><i>I would have slowed the whole thing down and I would have kept the concept of a pilot program. I would have tried to make that pilot program a bit more meaningful. (State/Regional-10)</i></p> <p>Providers should prepare for the transition ahead of time. This preparation could include assessing cash flow, providing training on billing processes, and discussing the need to be flexible for ongoing changes.</p> <p><i>You try to be really flexible with whatever instructions came your way because you could've been told one thing one day and the following day it's completely a different process. (Provider-05)</i></p> |

Table 3 Continued

| CMS Regulations: 10 Best Practices for Implementation of MLTSS | Study Lessons Learned |
|--|---|
| 2) Stakeholder engagement in the planning, implementation, and evaluation. | <p>Stakeholder engagement is critical for building relationships. Stakeholder engagement is also important as stakeholders can provide insights into the current system and could help develop the program based on their experiences. Families and providers should seek out opportunities to provide input to inform the new system.</p> <p><i>This is like any government program or activity, it is really based on relationships. So if you can build relationships built on trust, that you're going to provide accurate factual information and work with them in a partnership, then I mean it's really unlimited what you can accomplish. But when you're thrusting this upon the various communities that this is the way it's going to be and not taking into account their thoughtful, meaningful comments and recommendations that could save the state a ton of money, a ton of headaches and so forth, then why not do that? (State/Regional-02)</i></p> <p><i>I would have gone to the people who were going to be most directly affected, identified good strong contingencies of champions who would help lead the effort...this would instructively develop the program. (State/Regional-10)</i></p> |
| 3) Enhanced provision of HCBS including investing in employment. Services should be in compliance with ADA and Olmstead. | <p>MCOs in KanCare invested in employment initiatives through grant funding opportunities to reform employment systems in the state.</p> <p><i>The thing is that the state has been really high on people being employed in the community, which is a good thing...but the problem is that the work system itself is broke. It doesn't work very well unless you're the type of person that needs minimal support to get started, and get established, and then you don't really need a whole lot of follow up... The reality is most don't have those specific skills. (Provider-03)</i></p> |

Table 3 Continued

| CMS Regulations: 10 Best Practices for Implementation of MLTSS | Study Lessons Learned |
|--|---|
| 4) Align payment structures and goals, have performance based incentives for achieving stated goals to improve quality and reduce costs. | KanCare is utilizing this approach but study participants did not discuss this topic. |
| 5) Support for beneficiaries including providing education on enrollment and disenrollment options, access points to file complaints/concerns and grievance/appeals process. Include state oversight of grievance/appeals process. | Education and communication regarding the program is vital for providers and consumers. Education efforts should be done in advance and could be done in collaboration with existing key players in the IDD field to encourage participation. These efforts should answer any questions consumers or providers may have prior to implementation. Families also need to know who there points of contact are in the MCOs prior to implementation. <i>I would suggest that they try and get more transparency from the MCOs about structure and who is going to help with what and what they're capable of doing so that they can develop an understanding of who they need to talk to and when. (Provider-01)</i> <i>I think the biggest problem with KanCare is nobody really knows what it is. The communication in was bad. What I would do is develop a website, maybe hold some meetings once in a while. Give a list of phone numbers of people you can call if you've got a question. Is there an 800 number? Make it user-friendlier. Somebody new coming in? Give them some information and let them choose their plan. You can't implement something without explaining to people what it is and why it's necessary. It never works. (Family-01)</i> |
| 6) Person-centered process that moves away from the medical model approach and instead uses a quality of life perspective. | The TCM in KanCare completes the person-centered plan. Participants in this study did not discuss this topic. |

Table 3 Continued

| CMS Regulations: 10 Best Practices for Implementation of MLTSS | Study Lessons Learned |
|---|---|
| 7) Comprehensive integrated service packages that involve coordination of care across health care and LTSS specific to the needs of people with disabilities. | <p>The MCOs should attempt to hire people with experience in the IDD field to help with structuring care coordination and access to services process. The MCOs should consult with individuals who have expertise in IDD and adapt their policies and procedures to fit the needs of this population.</p> <p><i>I think one lesson learned is maybe to take a step back and truly look at all of the MCO practices and say, 'This has worked for us for a long time and for the majority of our members this will be just fine, but truly how does this impact the IDD population?' (State/Regional-13)</i></p> <p>In order to provide a comprehensive integrated service package the program may need to continue to utilize existing case management services in conjunction with designated care coordination staff from the MCO.</p> <p><i>The amount of knowledge that a case manager has about an individual just can't be replaced by a piece of paper, someone who sees them one time every six months or one time a year. So, that was a big piece that we were able to maintain targeted case management. (State/Regional-09)</i></p> |
| 8) Qualified providers and an adequate provider network. | <p>Provider network adequacy was difficult to achieve for those in rural areas and also to find providers to cover new services funded by managed care.</p> <p><i>There has been a real lack of consistency across the state and so I think the MCOs are pretty focused right now in making sure that services and things start up consistently across the state, so that the same guidelines and rules that apply in Western Kansas also apply in Eastern Kansas and Southern Kansas versus Northern Kansas. (State/Regional-11)</i></p> |

Table 3 Continued

| CMS Regulations: 10 Best Practices for | Study Lessons Learned |
|--|--|
| Implementation of MLTSS | |
| 9) Participant protections, safeguarding against abuse and neglect and ensuring continuation of services during appeals. | The state of Kansas operates ongoing oversight efforts, but study participants did not discuss this topic. |
| 10) Quality strategies should be in place and quality measurements should be transparent. | The Kansas Foundation for Medical Care is completing independent evaluations of the program's quality and these reports are publically available, but study participants did not discuss this topic. |

SECTION III: MANUSCRIPT TWO

Title Page and Journal Selection

Manuscript #2 Title: Family Caregivers as Needed Partners: Recognizing Their Role in Medicaid Managed Long-Term Services and Supports

Primary journal selection: *Journal of Policy and Practice in Intellectual Disabilities*

Reason for journal selection: Published by the International Association of the Scientific Study of Intellectual Disabilities. Content about policy development, service design, working methods, financial, administrative, and legal frameworks. This journal publishes manuscripts specific to family caregiver issues. Complete author guidelines can be found at <http://onlinelibrary.wiley.com/journal/10.1111/%28ISSN%291741-1130/homepage/ForAuthors.html>.

Secondary journal selection: *Intellectual and Developmental Disabilities*

Abstract

Background: Adults with intellectual and/or developmental disabilities (IDD) in the United States are supported by both formal Medicaid funded long-term services and supports (LTSS) and family caregivers. Lack of alternative housing options and wait lists for LTSS means the role of the family caregiver will be critical for years to come. Rising LTSS costs combined with goals to improve care coordination and access to services are driving more states to change the design of their LTSS systems to a Medicaid managed LTSS (MLTSS) approach. Best practices for implementing MLTSS for individuals with IDD include acknowledging the family caregiver role. **Specific Aims:** The current study's aim is to understand how family caregivers and their roles are recognized in MLTSS for adults with IDD in Kansas. **Methods:** Kansas was selected given their unique approach to MLTSS for adults with IDD, referred to as KanCare. In-depth semi-structured telephone interviews were completed with 31 stakeholders in Kansas, including statewide/regional representatives (N=13), service coordination providers (N=7), and family caregivers (N=11). **Findings:** Participants reported a lack of meaningful engagement of family caregivers in the planning and implementation of KanCare resulting in confusion and fear. Additional family support services were available in KanCare, but families had difficulty accessing them. No formal processes were reported for assessing the needs of family caregivers in KanCare and families found communications with managed care entities challenging. Families reported difficulties with taking on responsibility of managing in-home supports and there were concerns about being paid to provide care as a guardian. **Discussion:** Family caregivers play a critical role in MLTSS, including assisting with care coordination and access to services. However, their role was not formally acknowledged in MLTSS. Future research, practice, and

policy efforts should focus on promoting family caregiver assessments and identifying best practices for supporting family caregivers in MLTSS.

Background

Adults with intellectual and/or developmental disabilities (IDD) in the United States are experiencing longer life expectancies and improved quality of life, in part, due to the transition to more community-based care (Factor et al., 2012; Thomas & Barnes, 2010). Formal supports and services available to adults with IDD to promote independence and community inclusion in the U.S. are primarily funded through Medicaid long-term services and supports (LTSS) (Braddock et al., 2015; Connolly & Paradise, 2012). Spending on home and community-based services (HCBS) for adults with IDD makes up 70% of LTSS spending (Eiken et al., 2014; O'Keefe et al., 2010). However, Medicaid funded supports and services are not always sufficient to meet daily support needs, and many adults with IDD continue to need the support of a family caregiver (Braddock et al., 2015).

Family caregivers act as key partners in the current systems of care, with 71% of individuals with IDD in the U.S. needing the support of a family caregiver (Braddock et al., 2015). Between 2000 and 2011, there has been an almost four-fold increase in the number of adults with IDD relying on assistance from a family caregiver. Family caregivers are the biggest source of daily supports for individuals co-residing in households (Kaye et al., 2010; Larson et al., 2012). A United States Senate Long-Term Care Commission Report to Congress (2013) highlighted the critical role family caregivers play in our LTSS system as they help with daily care needs as well as with care coordination for their loved one. Unpaid family caregivers currently provide a majority of LTSS in the United States (Reaves & Musumeci, 2015). This ongoing support is likely to continue given wait lists for care and lack of alternative housing

options (Heller & Schindler, 2009). In a review of long-term care programs in developed countries other than the U.S., a commonality is formal systems to support family caregivers (Gibson, Gregory, & Pandya, 2003).

Family caregivers of adults with IDD are unique from other caregivers due to the longevity of their caregiving role (Haley & Perkins, 2004). A systematic literature review of studies exploring issues experienced by family caregivers of adults with IDD in the U.S. found that family caregivers report physical health, mental health, and economic consequences associated with their caregiving role (Williamson & Perkins, 2014). In order to address these issues, family support services can be provided which are designed to benefit the family with the ultimate goal to benefit the individual with IDD (Hecht & Reynolds, 2012). Family support services have been found to reduce stress, to reduce out-of-pocket spending on care, to assist with maintaining employment, and to reduce the likelihood for institutional placement (Hewitt, Agosta, Heller, Williams, & Reinke, 2013). Even though the current U.S. Medicaid LTSS system relies heavily on family caregiver involvement and benefits exist for supporting family caregivers, only 6.7% of spending on IDD services in the U.S. was for family support (Braddock et al., 2015).

Given their lived experience, family caregivers of adults with IDD have been described experts in informing current activities and future reforms of formal supports and services systems (Hewitt et al., 2013). Due to rising Medicaid expenditures, more states in the U.S. are considering or implementing reforms to their Medicaid LTSS systems for individuals with IDD (President's Committee for People with Intellectual Disabilities, 2012; Saucier et al., 2012). These changes involve moving from a fee-for-service model to a managed care approach entitled Medicaid managed long-term services and supports (MLTSS) (Saucier et al., 2012). The goals of

moving to MLTSS include improving quality of care while also controlling costs (Gifford et al., 2011). In 2012, there were seven states utilizing MLTSS for adults with IDD. By 2015, there were an additional six states, and four additional states planning to move to MLTSS in the next few years (National Association of States United for Aging and Disabilities, 2015).

The transition to MLTSS holds promise to positively reform existing systems by better coordinating care across health, behavioral health, and LTSS, which could result in improved access to needed supports (National Council on Disability, 2013; President's Committee for People with Intellectual Disabilities, 2012). However, concerns exist regarding the move to MLTSS including reducing access to care and increasing dependence on family caregiver involvement (Consortium for Citizens with Disabilities, 2012; National Council on Disability, 2013; Naylor, Kurtzman, Miller, Nadash, & Fitzgerald, 2015; President's Committee for People with Intellectual Disabilities, 2012). State specificity of Medicaid programs and the small percentage of individuals with IDD enrolled in MLTSS result in limited and mixed evidence regarding MLTSS's effectiveness (Connolly & Paradise, 2012; Saucier et al., 2012).

In response to uncertainty surrounding MLTSS for adults with IDD and the trend in states to implement MLTSS, Medicaid officials, experts in Medicaid policy, and advocacy groups have produced best practice recommendations regarding MLTSS for adults with IDD to help guide policy and practice (Centers for Medicare and Medicaid Services, 2013a; Consortium for Citizens with Disabilities, 2012; Dembner, 2012; National Council on Disability, 2013; President's Committee for People with Intellectual Disabilities, 2012; Truven Health Analytics, 2013). The Consortium for Citizens with Disabilities (2012) and the National Council on Disability (2013) include acknowledging the vital role of family caregivers and providing payments to family caregivers as support providers as best practice recommendations. A recent

study of MLTSS for adults with IDD in four states confirmed the critical role of family caregivers in MLTSS (Williamson et. al., in review). Additionally, states moving to MLTSS need to plan for stakeholder engagement, including family caregivers and self-advocates in the design, implementation, and evaluation of MLTSS (Centers for Medicare and Medicaid Services, 2013a, 2015; National Council on Disability, 2013; Summer, 2011; Truven Health Analytics, 2013).

Specific Aims

Family caregivers continue to play a critical role in MLTSS systems for adults with IDD. Best practices for MLTSS identify the importance of supporting family caregivers in MLTSS and it is crucial to understand how MLTSS programs can accomplish this aim (Consortium for Citizens with Disabilities, 2012; National Council on Disability, 2013). The current manuscript reports the results of one portion of a larger case study focused on the overall KanCare implementation experience. The study's overall objective was to describe the current implementation of MLTSS for adults with IDD and their family caregivers in a state (Kansas) that recently implemented MLTSS. Lessons learned from the Kansas MLTSS experience may potentially contribute to best practices for supporting family caregivers to guide future state and national MLTSS policies and programs. The specific research aim discussed in this manuscript was to understand how family caregivers and their roles were recognized in MLTSS for adults with IDD.

Method

Study Sample and Data Collection

Kansas was selected as the focus for this MLTSS implementation study, given their unique approach to MLTSS that has led them to be referred to as a “bellwether” state regarding

future MLTSS efforts (National Council on Disability, 2014b). Their approach is unique as they are the first state to utilize three private for profit managed care organizations (MCOs) and to include the full scope of available health, behavioral health, and LTSS in a managed care approach. Kansas reformed their entire Medicaid system to KanCare in 2013 under a Section 1115 demonstration waiver (KanCare, 2014). Adults with IDD began receiving health and behavioral health services under KanCare in January 2013 and their LTSS under KanCare in February, 2014 (KanCare, 2014).

A case study approach was utilized as an effective research method for policy implementation studies focused on managed care (Gold, 1999; Kaskutas et al., 2000). There are multiple stakeholders involved in the implementation and it was important to gain several perspectives on the family caregiver role acknowledgement in KanCare in order to improve reliability of the results (Kaskutas et al., 2000; Yin, 2014). Participants in this study represented state/regional groups, service coordination providers, and family caregivers.

After receiving University of South Florida Institutional Review Board approval, study recruitment began in January, 2015. A total of 31 participants agreed to complete in-depth semistructured telephone interviews. Participants representing statewide/regional groups and service coordination providers were recruited through direct email and mailings. Family caregiver participants were recruited through study flyer distribution and through snowball sampling. Family caregivers were provided a \$15 gift card for their time.

Thirteen participants represented statewide or regional groups involved in the implementation of MLTSS for the IDD population. Seven of the participants were service coordination providers who worked directly with individuals with IDD and their family caregivers to coordinate needed services and supports. These service coordination providers were

either a Targeted Case Manager (TCM) whom the family had already worked with prior to KanCare or they were the new Care Coordinators (CCs) from MCOs. In KanCare, the TCMs and the MCO CCs were tasked to work as a team alongside the family. Eleven of the participants were the primary family caregiver of an adult (over age 22) with IDD co-residing in the family home and utilizing KanCare. The family caregivers were all parents, with a mean age of their adult loved one with IDD 28 years old (SD=4.95, Range=22 years-38 years).

In-depth semi-structured telephone interviews were completed between February, 2015 and June, 2015, and ranged in length from 25 minutes to an hour. Interview protocols were pilot tested by individuals with expertise in IDD and managed care. Protocols included questions about their overall experience in KanCare and specific questions regarding the family caregiver role, how families were supported by KanCare, and how the needs of family caregivers were included in assessments under KanCare. The lead researcher completed all interviews which were recorded, with reflective research journal notes kept to inform the final analysis.

Data Analysis

The framework method was designed to guide qualitative research focused on health policy and was used to guide the analysis of this research (Pope et al., 2000). An *a priori* codebook was developed at the beginning of analysis including the larger themes of family caregiver role acknowledgement and family caregiver assessment. The framework method then led the researcher through seven stages (Gale et al., 2013). First, interviews were transcribed. Second, transcriptions were reviewed to familiarize the researcher with the data. Third, the transcriptions were coded identifying comment topics or themes discussed across interviews. Steps four, five, and six involved developing an analytic framework based on the codes and updated codebook. This framework was applied to additional transcripts, and then data were

charted into framework matrices. Framework matrices included a row for each interview, with the codes in the analytic framework were the columns, allowing for the researcher to review across individual interviews and draw comparisons across different interviewees. Steps four, five and six were an iterative process with the framework being updated and applied as more data was reviewed. Finally, the seventh step involved making interpretations from the framework matrices. All analysis was completed with the NVivo10 qualitative software package (QSR International, 2014). The validity of the findings was improved by having participants member check the responses in order to verify information accuracy (Silverman, Ricci, & Gunter, 1990). Feedback from participants was incorporated into the final results which were also reviewed by individuals with expertise in MLTSS to further enhance validity (Balbach, 1999; Silverman et al., 1990).

Findings

Stakeholder Engagement and Transition Experiences

It is considered best practice to include key stakeholders, like family caregivers, in the planning and implementation of MLTSS (Centers for Medicare and Medicaid Services, 2013a). Families in this study reported attending engagement events but left with questions unanswered and concerns not addressed. Participants reported feelings of confusion and fear during the transition into KanCare. The confusion and fear could have been reduced if stakeholders felt their concerns were addressed during stakeholder engagement efforts.

Families also described KanCare as making things seem more complex and cumbersome. In addition, families were also apprehensive as they did not feel individuals from the managed care groups fully understood the needs of their loved one with IDD. People were concerned going into KanCare because they didn't see evidence of acknowledging the importance of the

family caregiver role for adults with IDD. Table 4 contains illustrative quotes of key findings for this theme.

Family Caregiver Role Acknowledgement

The following results will discuss varying aspects of acknowledging the family caregiver role including role acknowledgement, family caregiver assessment, respite, communication challenges, and families as employers or paid family caregivers. Quotes highlighting topics discussed in the family caregiver role acknowledgement theme can be found in Table 5.

Role Acknowledgement

Participants identified the importance of providing support to family caregivers, but were not seeing evidence of this happening. The systems of supports were always complicated to navigate for families, but now with KanCare, they were reported to be more complicated. The support needs of aging family caregivers were also discussed and identified as important for MCOs to understand and plan for in their service delivery models. Families were supposed to discuss alternatives for day-to-day caregiving because of aging family caregivers. However, these plans were reported by participants to be short term issues versus looking at longer term future planning. Family support services were important, but at times, it took a crisis situation for family support services to be authorized.

In KanCare, some of the MCOs were able to provide new resources that looked at addressing crisis situations, in which a team of professionals could help families identify additional family support options. Providing additional family support resources for family caregivers were also identified as important to prevent caregiver burnout. If the MCOs could offer additional resources to avoid caregiver burnout, then there could be potential cost savings in MLTSS. However, there were also concerns that families were potentially experiencing less

in-home supports given the MCOs lack of familiarity with providing MLTSS and family support services.

Family Caregiver Assessment

Including the needs of family caregivers as part of the formal assessment process in MLTSS was one way to help plan for family support needs. Families were asked if their needs for support were ever discussed or if they were asked about their health and wellness during the assessment process. None of the families reported being asked any types of questions about their personal support needs or their health and wellness. The participants acknowledged that it would be good to ask family caregivers about their support needs in the formal assessment process. However, it was also assumed their needs would come up as part of conversations regarding the support needs of their loved one with IDD.

At times, when changes in services and supports needed to occur outside of the annual meetings, a needs assessment would be done. In this needs assessment, service coordination providers could identify if there was a need for additional paid in-home supports to help the family. Otherwise, family caregiver needs were potentially addressed in the Person-Centered Planning process, but this would not necessarily lead to the family caregiver getting the supports they needed.

Respite

Respite is a family support service option that allows family caregivers to take a break from their caregiving responsibilities. Prior to KanCare, respite was not a service offered through the Kansas Medicaid program, and the MCOs offered respite services as a value added service in their plans. Providers reported families using respite, but families indicated that it was difficult to access.

Communication Challenges

In order for families to take full advantage of available resources in MLTSS, they need to establish a relationship with their MCO contacts. Communication challenges were a big issue for families when trying to work with their MCOs. Participants discussed MCO CCs having large caseloads (80-140 people) either resulting in MCO CC turnover or making it difficult for them to establish good working relationships with families. This communication problem could also result in the MCO CC assuming natural supports provided by family members were adequate to support the individual with IDD.

Another communication concern was the use of mailings that families didn't always understand and might disregard. Families reported difficulties with contacting the MCOs to get their concerns resolved. Prior to KanCare, families worked directly with a Targeted Case Manager (TCM) to help advocate for and coordinate needed services. After KanCare, families worked both with their TCM and a MCO CC. A fear with the KanCare transition was that families would lose the advocacy support from the TCM. Participants discussed feeling that the TCM advocacy role had been reduced given the role of the MCO CC in decisions regarding needed supports. Additionally, participants felt it was a conflict of interest with the MCO CC trying to be advocate while also being employed by the MCO.

Families as Employers or Paid Family Caregivers

In some cases, family caregivers became employers managing all the in-home support staff after KanCare. This meant they were responsible for tracking hours of in-home supports and reporting these hours back to the MCOs. Families described the paperwork and processes as time-consuming, confusing, and difficult to manage.

Family caregivers themselves were also paid to provide the in-home supports to their son or daughter. Families in these situations reported having difficulty with paperwork and also getting timely payments. The Centers for Medicare and Medicaid Services proposed changes to existing Home and Community-Based Services (HCBS) program in their 2014 Final Rule (42-CFR-441.301). One issue in the CMS Final Rule was for states to address any conflicts of interest in their existing HCBS systems. Guardians of individuals with IDD in Kansas could be paid as a caregiver, which was interpreted by the Final Rule as a conflict of interest. As of June, 2015, paid family caregivers who are also guardians have to petition the Probate Court to continue in their paid caregiver role. For some families, there were often not other alternatives to providing in-home supports besides the family caregiver, given the level of support needed or due to residing in rural areas.

Discussion

Results from the current study indicate that the important roles of family caregivers in the lives of adults with IDD are not being fully recognized in MLTSS. Quality measures in MLTSS need more of a focus on addressing the well-being of family caregivers and ensuring their inclusion in communications (Academy Health, 2015). Families in this study did not feel their feedback was heard or questions answered in stakeholder engagement efforts. While new family support services were available in MLTSS, like respite, these services were not always easily accessible. Family support needs may also not be identified readily given the lack of a formal assessment of family caregiver health and wellness in KanCare.

Another concern regarding the move to MLTSS concerns the potential shift in additional care responsibilities onto family caregivers (Consortium for Citizens with Disabilities, 2012). Participants in this study expressed concerns that MCOs were misinterpreting natural supports as

meaning the individual may need less paid formal in-home supports. In addition, families took on additional responsibilities of managing in-home support providers. In some cases, where families were being paid to provide care, they were stressed about payments and also concerned about new conflicts of interest regarding payment for care as a guardian. More research is needed into the move to MLTSS and what these transitions mean for the roles of family caregivers in managing or providing paid supports (Kaye & Harrington, 2015).

Stated goals of KanCare are to better integrate care through improved care coordination, thereby increasing access to services to improve the health and wellness of individuals with IDD (KanCare, 2014). Providing caregiver education is an important step to encourage health promotion activities and preventive health care visits among individuals with IDD (Ervin, Hennen, Merrick, & Morad, 2014). Family caregivers are an important resource for MCOs to recognize methods to best coordinate MLTSS (Saucier & Burwell, 2015). Ideally, transitioning to MLTSS could enhance care coordination, reducing the level of involvement of the family caregiver by increasing access to needed services (Naylor et al., 2015). However, communication challenges, experienced in KanCare, detracted from achieving better coordination of care. In a recent evaluation of Medicaid managed care for individuals with IDD, researchers identified that only 26% of care coordination staff reported occasionally inquiring with family caregivers about their needs (Heller, Owen, & Crabb, 2015). Clearly there is a need to promote more communications with family caregivers in MLTSS.

There are calls to action to promote both a person-centered and a family-centered approach to the delivery of LTSS in the U.S. (Reinhard et al., 2014; U.S. Senate Commission on Long-Term Care, 2013). One recommendation to encourage a family-centered approach is to have government funding pay for family caregiver assessments as part of MLTSS (Feinberg &

Houser, 2012). An environmental scan of existing HCBS waivers or LTSS programs in the U.S. identified that only one-third of states were completing some level of family caregiver assessment (Kelly, Wolfe, Gibson, & Feinberg, 2013). There were no formal processes in place in KanCare to evaluate the needs of family caregivers. Identifying the needs of family caregivers as they age will be especially important as longer duration of caregiver has been associated with fair to poor health amongst caregivers (National Alliance for Caregiving, 2015; Owen, Crabb, & Heller, 2015).

This study has limitations including it was a cross-sectional view of MLTSS implementation, limiting the perspectives of participants to point-in-time impressions of the implementation. However, the timing of the study is important to inform future MLTSS efforts for individuals with IDD rapidly expanding in new states (National Association of States United for Aging and Disabilities, 2015). A qualitative approach allowed for openness to new ideas but makes it impossible to make broad generalizations. The process of member checking results with participants and having results reviewed by professionals with expertise in MLTSS for the IDD population further improved both the dependability and transferability of the results.

This study has implications for research, practice, and policy. More research is needed into best practices to support family caregivers of adults with IDD in MLTSS. In particular, research could focus on identifying methods for enhancing communications and incorporating the role of family caregivers to make care coordination more effective (Saucier & Burwell, 2015). New CMS MLTSS regulations support identifying best practices for stakeholder engagement, but reported there are not yet clearly defined adequacy standards for such efforts (Centers for Medicare and Medicaid Services, 2015). In practice, states could work to identify best practices for effectively engaging family caregivers as stakeholders in the planning,

implementation, and evaluation of MLTSS. Policies could promote inclusion of family caregiver assessments in MLTSS. At a minimum, these assessments should address the well-being of the family caregiver, their changing support needs over time, and identify plans for future caregiving (Kelly et al., 2013; Williamson & Perkins, 2014).

Table 4: Illustrative Quotes for Stakeholder Engagement and Transition Experiences Themes

| Topic | Quote(s) |
|--|---|
| Stakeholder didn't feel heard in engagement efforts | <p><i>The meetings that they had for parents and caregivers did not answer any questions. ...With my son it saves the state a lot of money for him to be here rather than in a group home or in a state hospital. So, why are they not listening to us? (Family-04)</i></p> <p><i>The families were given the opportunity to provide input. I am not sure what was done with that input, but they were able to give it. (State/Regional-05)</i></p> |
| Confusion and fear during transition | <p><i>We were told that the traditional Medicaid was going away and that the MCOs were taking it over and we were very concerned. (Family-02)</i></p> <p><i>The biggest confusion was when KanCare was put into place, there's nobody that understood the rules. They didn't know how KanCare starting was going to affect the doctors, their medications, whether they go to any long-term care or anything. (Family-01)</i></p> |
| MLTSS made more complex | <p><i>It just seemed like it was another meeting that we had to have, that we went over the same things that they already had in their system, that I just didn't feel was necessary. (Family-08)</i></p> <p><i>It was too cumbersome. There was too much paperwork. (Family-04)</i></p> |
| MLTSS felt unfamiliar with needs of their loved one | <p><i>We already had services for our son. So that didn't change anything too much. I think the thing that we noticed most was nobody knows anything about our child. (Family-07)</i></p> |
| Lack of appreciation of family caregiver role created fear | <p><i>I think, in general, the reason that people were so frightened and had so much animosity about this was they felt that those who were pushing the inclusion of IDD services into KanCare did not appreciate the role of the families in the lives of their family member with disabilities. (State/Regional-04)</i></p> |

Table 5: Illustrative Quotes for Family Caregiver Role Acknowledgement Theme

| Sub-Theme | Topic | Quotes |
|----------------------|---|--|
| Role acknowledgement | Family important role and new system more complicated | <i>So families are clearly a big part of this puzzle for a lot of people. (State/Regional-02)</i> |
| | MLTSS made system more complex for families. | <i>The family support thing is pretty big. It's a huge, huge struggle, to navigate the system, and to figure things out. The system has never really been that simple. Now that it's privatized its that much more complicated. (Provider-03)</i> |
| | Families not getting proactive support services | <i>So I think publicly they recognize that families play a huge role and a lot of families want to continue playing these roles, however it didn't translate to anyone getting help, until basically it hits the fan. (Provider-03)</i> |
| | New resource for families in crisis under MLTSS | <i>Families, I think especially those that were experiencing crisis, now have access to more people that will be able to see the whole picture and can connect to things that weren't there before. (State/Regional-13)</i> |
| | Avoid caregiver burnout | <i>We're taking a look at when somebody is saying that they need respite...we are looking at those cases and providing additional supports when we can, in order to prevent that caregiver burnout...If we do a temporary increase for somebody in services and support so that their caregiver can take care of themselves and in the long run when that caregiver continues to be able to provide that care later on in life. It's a long term cost savings. (State/Regional-11)</i> |
| | Misunderstanding the role of natural supports | <i>I think what we've seen is that they are significantly taxing and they're taking advantage of natural supports to the point of cutting people's hours by saying, 'Oh we have natural supports that can do that'... just because of who they had living in their home, they wanted those people to provide 16 hours of support a day to the person. Because you have someone living with you, then they have to take care of you 16 hours a day? That's not what natural supports are about. (State/Regional-12)</i> |

Table 5 Continued

| Sub-Theme | Topic | Quotes |
|-----------------------------|--|--|
| Family caregiver assessment | Family caregivers not asked about their needs, health or wellness | <i>I don't know if we present ourselves as being okay but they don't ever come out and ask me how we're dealing with it mentally, physically... they don't really ask us how we're doing specifically. (Family-01)</i> |
| | Assumed family caregiver needs would come up in conversation | <i>I find that that comes up very naturally in questions or in conversations. I don't think it's [asking about family caregiver needs] necessarily a part of our formal assessments, but it definitely comes up when there's discussions about, Gosh, how's are things going?' It doesn't really say 'What do we think is going to happen?' A lot of times parents are really willing to be like 'Gosh, I just found out from a doctor that I've got this health problem and I don't know - I'm really stressed because I don't know how the member with IDD is going to be taken care of? (State/Regional-11)</i> |
| | Needs Assessment process identifies need for in-home supports | <i>The needs assessment is what identifies when the family caregiver can give natural support and when do they need paid support. (State/Regional-03)</i> |
| | Person-centered plan does not include process for accessing needed family support services | <i>So let's say that right now, my 80-year-old mother is my primary caregiver. She's suffering from dementia and has her own health and medical issues going on, and it's probably unlikely that she's going to be able to continue to serve as my primary caregiver for an undetermined amount of time. The person-centered support plan would address that. The person-centered support plan however would not say, 'Okay. In response to this, we're going to contact the Area Agency on Aging and see if we can get your mom qualified for some home health care.' The person-centered support plan is just built around just the person with the developmental disability. Actually referring for or setting up those services for family members would be done through a different entity. (State/Regional-10)</i> |

Table 5 Continued

| Sub-Theme | Topic | Quotes |
|--------------------------|--|---|
| Respite | Families appreciate respite available | <i>They really appreciate being able to have respite because that was not an option at all to have any time off for the parents when they needed it. (Provider-07)</i> |
| | Families have difficulty accessing respite | <i>What we really could use is some respite. That's kind of hard to do...yes you can get the funds, you get so many hours a month, but finding somebody who could provide that service...is a different story. The respite just isn't out there. (Family-06)</i> |
| Communication challenges | Lack of relationship between family caregiver and MCO Care Coordinator | <i>It's hard for a family to have faith in the Care Coordinator that's here one day and gone the next. (State/Regional-07)</i> |
| | MCO Care Coordinators need more education on family situations | <i>I think that, generally speaking, the MCO Care Coordinators that meet with families tend to try to get to know their families...however, that can be a double-edged sword, because if the family is very, very involved and then sometimes they are not able to identify issues...because they meet with them once a year really. They tend to go, 'Oh well, he lives with mom and dad. They should be able to provide all of their support.' So, sometimes you really have to educate those Care Coordinators that don't see the whole picture. (State/Regional-03)</i> |
| | Communication from MCOs to families difficult to understand | <i>It's not that families can't change but families need to be really made aware. A lot of times, it's more verbal than it is all these written jargon letters that their then like, 'Well, I don't even know what that meant and I just threw it in the trash.' (Provider-02)</i> |
| | Families have difficulty communicating to the MCO their needs | <i>Their contact numbers ring, but nobody ever answers. It's very difficult to get in touch with anyone. ...and of course their secured emails, they send emails all the time that you can't open. Since November, I've been calling, I've been emailing, I've sent them letters...I've talked to so many people and I'm blue on the face. The emails, they don't get them evidently, because mine aren't secured and so there's just a total lack of communication. (Family-02)</i> |

Table 5 Continued

| Sub-Theme | Topic | Quotes |
|-----------------------|---|---|
| | Lack of advocacy for family caregivers | <i>There's nobody to advocate for the family anymore because the Care Coordinators can't advocate because they work for the MCO. Targeted Case Managers don't really even have a say anymore. So there's really nobody helping families through. (Provider-04)</i> |
| Families as employers | Families as employers report confusion with processes | <i>Well after KanCare, I don't know what changed, but after KanCare...now, we are the employers and we have to fill out all the paperwork for all the employees and we have to manage all the employees and we have to develop files for all the employees...now we have to manage spreadsheets with each person, what hours they worked, what items they did and toss it all up in a bow and give it to somebody so they can push a button...So why is that pushed off on the families? We'd much rather be interacting with our adult getting ready for his long-term settlement. (Family-01)</i> <i>The problem is that the MCO will send me this printout with dates and these numbers and a dollar amount...there's no way for the guardian or the family to figure out - you can't figure out how many hours you used. (Family-05)</i> |

SECTION IV: CONCLUSIONS AND RECOMMENDATIONS

Theoretical Implications of the Study

Bronfenbrenner's ecological model (1979) provided the framework to discuss how policy implementation efforts translate from ideas into practice addressing aims one through three of the study. The unified theory of FQOL provided the justification for exploring specifically aim three of the study focused on the family caregiver role acknowledgement (Zuna et al., 2011). To date, there is not a systems level policy implementation framework available specific to MLTSS. The current study results will be explored in light of these theories to further advance their applicability in future research efforts.

Bronfenbrenner's Ecological Model

Bronfenbrenner's ecological model utilizes four levels of influential factors to explain relationships between policies, programs, and people. These four levels are: 1) the macrosystem; 2) the exosystem; 3) the mesosystem; and 4) the microsystem. Study results will be discussed referring to each level of Bronfenbrenner's ecological model as it applies to MLTSS implementation.

The macrosystem refers to the larger philosophical views regarding MLTSS, including the national guidance on such efforts from CMS. At the macrosystem level, study participants discussed managed care goals of reducing costs while improving access to services. Access to services could be accomplished through establishing a comprehensive provider network, providing new services, and promoting preventive care. In addition, the importance of

approaching MLTSS implementation with a great deal of planning and longer time-lines with pilot testing was discussed as critical for improving the implementation experience. Federal oversight occurred through referencing the best practices recommendations from CMS and also through addressing the underserved waiting list needs.

The exosystem is the external yet more immediate environment in which the policy implementation occurred, or in this cases the statewide efforts. Participants identified state oversight efforts to ensure continuity of care for individuals with IDD as crucial to making the transition occur without major life interruptions for people with IDD and their family members. While participants were not always certain of the influence held by oversight committees, they were still found to be essential. It was important for stakeholders to understand how the oversight efforts were working to influence MLTSS operations. Adequate stakeholder engagement in the planning and implementation of MLTSS could potentially help alleviate fears and inform program development both before and throughout the implementation process. One of the concerns regarding MLTSS was the lack of LTSS understanding amongst MCOs and the fears that MCOs would approach LTSS in a medical model (President's Committee for People with Intellectual Disabilities, 2012). Study participants discussed the importance of MCOs hiring people from the IDD field to help inform their policies and procedures. It was noted that MCOs contributed their health care knowledge and expertise to help address complex health and wellness issues faced by people with IDD. The MCOs were also able to contribute additional value added services under Medicaid given their corporate structures allowing for more flexibility with funding.

The mesosystem explored the interactions between the family caregiver of adults with IDD and their service coordination providers. Regarding the provider network, it was critical for

families to maintain existing providers and to have accurate information regarding providers contracting with MCOs. Issues with billing and provider payments proved problematic to accessing durable medical equipment and for families managing provider payments. In order to better inform family caregivers and individuals with IDD, participants identified that consumer education materials needed to be provided in more accessible ways in order to ensure choice.

Care coordination and access to services were also considered part of the mesosystem in MLTSS implementation. Family caregivers identified the importance of having a point of contact to help with coordination of services for their loved ones. Families had trouble identifying the roles of their MCO Care Coordinator (CC) and their existing Targeted Case Manager (TCM) after implementation. It was particularly confusing during the evaluation processes for services, as evaluation instruments used by both overlapped. The MLTSS system felt more complex to navigate. Ongoing access to pre-MLTSS care coordination resources, the TCM, was important as this individual helped the family navigate the new system. Clear definition of roles should be communicated to families in advance. In addition, the MCO CCs had very large caseloads making it hard for them to be in regular contact with families. This further highlighted the importance of the continuing role of the TCM. A collaborative approach between the old and new service coordination providers may potentially help ease transitions into MLTSS.

KanCare was tasked with integrating across health care and LTSS so participants discussed access to services including: behavior management; behavioral health; crisis; dental; durable medical equipment; health; LTSS (including employment); case management; and value added services. Future evaluations of MLTSS utilizing Bronfenbrenner's ecological model

should include the full scope of services, as MCOs may be expected to cover more than just LTSS.

Finally, the microsystem included the experiences of the family caregiver and their loved one with IDD in light of MLTSS. This study included the discussion of the family caregiver role acknowledgement. Families identified not feeling that their questions or concerns were answered prior to implementation, thus creating feelings of fear and apprehension. This finding further highlighted the importance of stakeholder engagement. After implementation, families continued to identify communication challenges with the MCOs and also not having a relationship with their contact at the MCO to get questions answered.

In addition, family caregivers reported they were not asked about their needs, health, or wellness in light of their caregiving role. Providers and state/regional level participants identified the importance of the family caregiver role, but often assumed their needs would come up naturally in conversation instead of formally being assessed. Respite services should be made available to family caregivers to avoid burn out. However, it is not always easy to find respite providers. During MLTSS implementation, it was also important to consider the roles of families being paid to provide care or operating as employers of record for their support staff. In these situations, families experienced stressors related to managing the billing processes.

Bronfenbrenner's ecological model provided a useful framework to frame the results of the current study related to MLTSS policy implementation efforts. There are no definitive boundaries in the ecological model, as constructs can overlap across levels of the model. This study found results for aim one centered in the macrosystem and exosystem levels, aim two at the exosystem and mesosystem levels, and aim three at the microsystem level. Table 6 contains

a summary and proposed concepts to include in future research efforts regarding MLTSS implementation for adults with IDD utilizing Bronfenbrenner’s ecological model.

Table 6: Proposed MLTSS Implementation Concepts in Bronfenbrenner’s Ecological Model

| Macrosystem | | | |
|--------------------------------|--|--|----------------------------|
| <u>Managed Care Goals</u> | <u>Planning</u> | <u>Federal Oversight</u> | |
| Access | Long timeline | Wait lists | |
| Cost | Pilot testing | CMS best practices/guidelines | |
| Prevention | | | |
| Exosystem | | | |
| <u>MCO Resources</u> | <u>Stakeholder Engagement</u> | <u>State Oversight</u> | |
| Health care knowledge | Alleviates fears | Continuity of care | |
| Acquire expertise in IDD field | Informs program development | Oversight committees | |
| Flexibility with funding | Stakeholders need feedback on how input was used | | |
| Mesosystem | | | |
| <u>Provider Network</u> | <u>Consumer Education</u> | <u>Care Coordination</u> | <u>Access to Services</u> |
| Accurate provider lists | Accessibility & choice | Roles clarity | Behavioral |
| Maintaining providers | | Caseload | Crisis |
| Billing and payment concerns | | Collaborative relationships | Dental |
| | | Continuity of existing case management | DME |
| | | Evaluation process | Health |
| | | | LTSS (employment, respite) |
| | | | Value added services |
| Microsystem | | | |
| <u>Stakeholder Engagement</u> | <u>Family Caregiver Role Acknowledgement</u> | | |
| Questions answered | Caregiver assessment | | |
| Concerns recognized | Respite | | |
| | Communications with MCO | | |
| | Families as employers or paid family caregivers | | |

Unified Theory of FQOL

The unified theory of FQOL (Zuna et al., 2011) posits that changes to programs and policies have an influence on not only the individual with IDD but also their family support system and ultimately their family quality of life (see Figure One). The current study did not explore outcomes related to family quality of life, but this theory was used to express the

importance of the family caregiver role in the lives of adults with IDD in MLTSS implementation.

Systemic Factors

The unified theory of FQOL identifies three systemic factors that indirectly influence individuals with IDD and their family caregiver: systems; policies; and programs. Aim One was focused on system-wide implementation experiences and was informed by these systemic factors. A system is the first systemic factor and includes large networks intended to meet people's needs, (e.g., MLTSS in Kansas). Families identified not feeling included or heard in the planning and implementation of the systems change to MLTSS in Kansas. This lack of engagement contributed to families expressing feelings of worry and confusion during the implementation process.

Policies are the guidelines and regulations that provide structure to the MLTSS program. In Kansas, the state developed guidelines for the MCOs to adhere to in the implementation of the KanCare for adults with IDD. One such policy involved the MCOs ensuring continuity of care for individuals with IDD by the MCOs allowing out-of-network providers for a period of time and the state reviewing any service changes proposed. Families in this study did not report any significant changes to services or supports after the transition to MLTSS, likely due to these state oversight efforts. However, other policies created some strain on families including family caregiver becoming employers of record, and managing support staff billing. Families who acted as paid family caregivers also expressed difficulty with timely payments and the billing processes in KanCare.

Finally, programs refer to the groups responsible for overseeing service delivery, which in this study, were the MCOs. Families described education efforts and materials provided by

MCOs at times being confusing. They had trouble with accuracy of provider handbooks and difficulty identifying how or who to contact at the MCO if they had a question or concern.

Families sought assistance primarily from the existing Targeted Case Manager who would then work directly with the MCO to help resolve concerns.

Individual and Family Level Performance Factors

The unified theory of FQOL classifies three individual and family level performance factors: 1) services; 2) practices; and 3) supports; which directly impact individuals with IDD and their family caregiver. Study results for Aim Two explored care coordination, and access to services in MLTSS reflect these performance factors. The services construct refers to the formal services provided in MLTSS. In KanCare, families largely identified maintaining their needed services for their family member with IDD. Families identified the ability to keep their existing providers as critical given the long-term existing relationships and difficulty in finding new providers. Acquiring durable medical equipment (DME) took longer than expected.

Alternatively, families were asked to pay for equipment up front due to billing issues and reported delayed payments to DME providers. Dental services were newly available, but there were limited providers and long wait lists. Other value added services, including respite, were noted as useful, but it was hard for families to find providers.

The performance factor practices refer to the policies and procedures through which services are provided. In this study's case, this was referred to as care coordination. Families identified working with their TCM and a MCO CC in order to qualify for, identify, and obtain needed services. After KanCare, families identified care coordination as becoming more complex and confusing. There was uncertainty regarding the role of their TCM versus their CC. It was also discussed that MCO CCs didn't have adequate time to get to know families and their

individual situations, so families continued to rely on their TCM for ongoing care coordination support.

Supports is a performance factor in the unified theory of FQOL which denotes the informal support the individual with IDD and family members receive from the community at large. The MCO CC's large caseloads resulting in limited time with families made it difficult for a relationship to form with the families in order to fully understand the scope of their existing informal supports system. This lack of familiarity was why the ongoing relationship with the TCM was identified as important. The TCM and MCO CC worked together to review informal supports available in identifying needed formal supports and services.

Family Unit and Individual Characteristics

Within the family unit there are both individual and family-wide beliefs and demographic characteristics that can also influence family functioning and FQOL. Aim Three of the study specifically identified how the family caregiver's role was acknowledged in MLTSS and can be addressed further with constructs at this level. Participants discussed the need to identify supports for family caregivers as they age and can no longer provide the same level of care. However, according to respondents, the current evaluations utilized in KanCare do not formally recognize the role of family caregivers or how their needs might change as they age. Family caregivers did not report being asked about their health, wellness, or support needs. Providers noted that the needs of family caregivers were assumed to come up naturally in conversation about the individuals with IDD. The needs of family caregivers may arise in the person-centered support plan, but there were not specific questions regarding the family caregivers in this process, indicating KanCare was utilizing a more person-centered versus family-centered approach.

Study Strengths and Limitations

This study has limitations. There are challenges to making managed care research relevant to policy makers. Some specific issues with managed care research that make transferability to larger policy issues challenging are the state specificity of programs and the complexity of each program (Gold, 1999). A limitation of this study is that it is restricted to one state, which may hinder the ability to draw broad recommendations for MLTSS policy and practice. However, a strength of the study was that it occurred at a time in which MLTSS was rapidly expanding across states. Therefore it was a critical time to inform policy and practice. Additionally, CMS (2015) recently proposed new nationwide rule changes governing MLTSS, which reflect best practices, making study results informative to states proposing implementation of MLTSS under new regulations.

Another limitation of the current study was that while it looked at implementation, it took a point-in-time view of the implementation process. The study would be improved if a more longitudinal approach was used with more than one interview with each subject occurring over a designated time period. Perhaps some of the challenges described with the implementation could be resolved further into the process, and resolution of these challenges faced would be informative to future MLTSS policies. Despite the limitations of a point-in-time view, the current study increased reliability of the findings by capturing differing perspectives and multiple sources of information to triangulate understanding (Yin, 2014).

Nevertheless, there is always a chance for participation bias. It is possible that individuals who were more likely to participate had very different views regarding MLTSS implementation as compared to those less likely to participate. The implementation of KanCare was not without great opposition and political discussion (Marso, 2014). The politically heated

environment created recruitment challenges for those stakeholders involved directly in state government activities. The current study provides perceptions regarding MLTSS implementation from a sample of Kansans and it is possible that those who chose to not participate in this study had varying or opposing views regarding the KanCare implementation process.

The case study approach is a method recommended for policy implementation studies and for research concerning managed care and thus was selected as the approach for this study (Gold, 1999; Kaskutas et al., 2000). The concept of parsimony calls for the research design selected to fit what is needed to answer the research aims without going beyond what is necessary (Crosby, DiClemente, & Salazar, 2006). The case study was found to be an appropriate and parsimonious method to address the study aims. A strength of the case study approach is it doesn't assume a predictable path, so it is open to new ideas (Yin, 2014).

There is not consensus in qualitative research regarding adequate sample size for saturation, it has been proposed that saturation can be reached in as little as 12 interviews (Guest, Bunce, and Johnson, 2006). After completing an analysis of existing qualitative studies, Marshall, Cardon, Poddar, and Fotenot (2013) concluded that case studies should include anywhere from 15-30 interviews. The use of qualitative semi-structured interviews in this study allowed the researcher to gather great depth of information on implementation experiences. While one cannot assume the perspectives of those participants in this study were representative of all Kansans, there were repeated ideas throughout data collection indicating saturation was reached from the various stakeholder perspectives. In the current study, no additional changes to the codebook were made after the twenty-second interview pointing towards reaching saturation of core concepts related to MLTSS implementation.

Efforts were made to also improve the reliability and validity of the study findings. The use of the framework method to guide data analysis created a chain of evidence as it created an audit trail from the raw data to the final themes by using matrices (Gale et al., 2013). Bias was reduced and the case study strengthened by combining data collection and analysis in a constant comparative method. A constant comparative method was used in the framework method in the development and application of the analytic framework and in charting the data into the framework matrices (Gale et al., 2013). This allowed the analysis to guide whether additional data was needed in order to explore contradictory information (Balbach, 1999; Kaskutas et al., 2000).

External review of the data collection and analysis improved validity of the findings. Content validity of the interview protocol was confirmed by having two experts in MLTSS and from the IDD field review the interview protocol and pilot test the questions (Chaudry, Brandon, Thompson, Clayton, & Schoeps, 2003). In addition, preliminary study results were provided to those interviewed for member checking in order to verify information accuracy (Silverman et al., 1990). Finally, professionals working in MLTSS policy reviewed the analysis and results to further enhance validity (Balbach, 1999; Silverman et al., 1990). By providing a clear description of data collection and analysis, as well as planning for both internal and external review of data collection and analysis, this allowed others to judge the conclusions drawn from the study and also the transferability of the findings to other states and to national policy (Pope et al., 2000).

Implications for Research

This study has implications for public health and behavioral health research. Integration of behavioral health and physical health is a high priority in MLTSS (Connolly & Paradise,

2012). KanCare was tasked with integrating care across health and behavioral health. In the current study, the MCOs were reported to be working on behavioral health initiatives including providing access to specialized care coordination and crisis services. Behavioral health and public health researchers could collaborate to further explore best practices for service integration based on the KanCare experience (Kronick, Bella, & Gilmore, 2009). More research is needed to understand effective care coordination models which successfully identify mechanisms to integrate across health and behavioral health services (Saucier & Burwell, 2015).

Currently, there is no standardized assessment process across MLTSS programs, with programs generally assessing health care needs, behavioral health needs, activities of daily living, instrumental activities of daily living, informal caregiver supports, and cognitive status (Ingram, Lind, & Ensslin, 2013). Participants in this study did not describe evaluations including informal caregiving supports outside of the number of hours of support provided. Future research could explore adding assessment tools to address caregiver health and wellness, evaluating the utility, reliability, and validity of available caregiver assessment instruments. Under the assumption that states utilizing a formal family caregiver assessment are taking a family-centered approach to care, future research could also look at comparisons between states utilizing a person-centered approach versus those using a family-centered approach.

Additionally, based on the results from this study, future quality evaluation instruments could consider adding the following domains: care coordination process; access to care issues; effective communication strategies for consumer education and consumer choice; and successful engagement of stakeholders to inform program development. The development of a survey instrument used in future research efforts on MLTSS would allow for quantitative analysis and comparisons across groups, improving transferability of research results (Kaskutas et al., 2000).

Also, if a state was rolling out MLTSS with some of its population still in fee for service and others service delivery models in MLTSS, then a quasi-experimental design could be used in which these two populations are compared on their responses to a survey about receiving LTSS. The study could explore differences and similarities in care coordination and access to services between the two groups.

Another stated goal of KanCare identified by study participants was to address costs. However, this was not addressed in the current study. A future study could look at Medicaid billing for MLTSS enrolled participants compared to those in fee for service to identify differences in cost and care utilization. A longitudinal approach to future research could also explore changes over time in program implementation. A particular area of focus for future research could be best practices for care coordination, since this was identified in this study as a critical piece in order for individuals with IDD and their family caregivers to navigate systems. Effective care coordination for individuals with complex needs, including individuals with IDD, is a suggested mechanism to help integrate care, improve access, and reduce costs (Saucier & Burwell, 2015). Without support of some type of the case manager or care coordinator, participants might not successfully access the full scope of available services and supports. Future research could compare differing care coordination strategies across states to identify best practices.

Implications for Public Health Practice

This research study has implications for public health practice. A recent report from the Centers for Disease Control and Prevention estimated that 22% of U.S. adults reported some type of disability (Courtney-Long et al., 2015). Amongst these individuals with disabilities living in family households, it is the family members who will be the largest source of daily supports in

long-term care (Kaye et al., 2010). With one in five Americans reporting some type of disability and the projected aging of the U.S. population potentially resulting in more people with disabilities, the demand for long-term care and our reliance on family caregivers are likely to grow.

These aging and disability demographics point to the increasing trend amongst states to move LTSS into a managed care model to control costs and improve quality is not likely to slow down. However, results from this study indicate the family caregiver role to date was not being formally acknowledged in the planning for supports and services in MLTSS. The Consortium for Citizens with Disabilities (2012) provided several recommendations for implementing managed care for individuals with IDD. In particular, the MCOs could formally acknowledge the critical role of the family caregiver by providing adequate family support services, avoiding over-reliance on family caregivers to achieve cost-savings, and involve family caregivers in the planning, implementation, and evaluation of managed LTSS programs. These best practices should be considered as states are reforming their LTSS programs. In particular, it will be important for these programs to promote the use of family caregiver assessments in daily practice.

Adults with IDD continue to experience health disparities. One goal in KanCare was to allow for better access to preventive care in order to reduce these disparities. *Healthy People 2020* includes goals to increase the availability to and accessing health promotion programs for people with disabilities (U.S. Department of Health and Human Services, 2015). In KanCare, the MCOs were able to have more financial flexibility in their service offerings to include access to preventive care and health promotion activities. Although family caregivers who volunteered for this study did not report accessing these services, the possibility still remains for them to do so in

the future. Other MLTSS programs could consider adding access to health promotion activities as a stated goal of their program. Adults with IDD also experience co-morbid mental health conditions. In this study, the MCOs were investing in behavioral health resources through specialized Care Coordinators or crisis teams. Access to needed behavioral health services needs to remain a priority in MLTSS for adults with IDD.

Healthy People 2020 also seeks to reduce the number of people with disabilities reporting access issues to receiving health care services (U.S. Department of Health and Human Services, 2015). Respondents in this study identified access issues for dental care a problem given the limited number of dental providers offering services in KanCare and the limited services offered to people with disabilities. Future MLTSS programs could work to ensure access through provider training and support to encourage health care provider participation in services for individuals with IDD.

Reducing unemployment rates amongst people with disabilities is also a stated goal in *Healthy People 2020* (U.S. Department of Health and Human Services, 2015). Increasing employment amongst individuals with disabilities in Kansas was also a priority in KanCare. While respondents didn't discuss changes in employment rates, they did note the investments MCOs had made in employment reform to help encourage competitive employment amongst individuals with IDD.

Implications for Policy

Finally, this research study has implications for policy. The study was completed during early stages of the KanCare implementation process. Since it was early in the implementation, some of the challenges discussed might have been inevitable. However, the insights from study

participants are still informative to future MLTSS policy, as other states may face similar challenges in their MLTSS implementation efforts.

The Centers for Medicare and Medicaid Services (2015) recently proposed new regulations regarding the implementation of MLTSS, the first such guidance since 2002. Within these proposed regulations, several best practices are included: adequate planning; ensuring access to services; effective care coordination; adequate consumer education; and stakeholder engagement. These best practices, potentially becoming regulations guiding new and existing MLTSS programs, will be discussed based on results of this study to guide future policy. Keeping in mind the early stages of the KanCare implementation process, disability advocacy groups can utilize the information gleaned from this study to inform their outreach and education efforts to consumers, third-party payers, decision makers, policy makers, and state-level administrators. Policy decision makers can also consider these lessons learned in future MLTSS policy directives.

First, CMS proposes programs plan for adequate time to complete planning processes in order to ensure a smoother transition into MLTSS. Respondents in this study discussed the need for utilizing a longer planning timeline that would have allowed for implementation of a full pilot program. In KanCare, there was a pilot program, but participants felt it was too rushed. Given more time, results of the pilot program could have been used to make system corrections before full implementation. Additionally, participants noted that it is important in the planning phases to take time to learn how the current system works and how to best fit MLTSS within existing resources. With longer planning timelines, participants indicated that providers could be better prepared, with more training on new billing processes. While there are no recommended standards for the exact length of a preferred planning timeline, states developing MLTSS policy

could at least consider ensuring enough time to evaluate current system capacity and pilot the MLTSS program utilizing pilot feedback prior to full implementation.

Second, CMS suggest programs ensure stakeholder engagement in the planning, implementation, and evaluation of programs. Study participants discussed stakeholder engagement as critical for building relationships and establishing trust. Stakeholders could identify gaps in the current system and areas of priority for the new MLTSS implementation. While there were opportunities in KanCare for stakeholder engagement, participants in this study reported uncertainty regarding what was done with their feedback. States considering moving to MLTSS could include clear standards for engaging stakeholders and mechanisms for providing feedback to stakeholders on how their input helped design and drive the new MLTSS programs.

Third, CMS identifies that MLTSS programs should work to enhance the delivery of LTSS by investing in employment of people with disabilities. In KanCare, the MCOs were able to invest funding for projects to help promote more competitive employment in the state. Results of these efforts is not yet known, but policy developers could ensure provisions in MLTSS for addressing reducing unemployment rates and increasing competitive employment amongst individuals with IDD.

Fourth, CMS noted the importance of providing beneficiary support for grievances and appeals and also providing consumer education so consumers are informed of choice and enrollment options. Participants in this study identified families needing to know in advance clear points of contact with MCOs to resolve issues faced in MLTSS. Also, study respondents suggested education efforts should be completed in partnership with existing IDD organizations in the state to help encourage consumer participation. Consumer education strategies need to be clearly articulated in future MLTSS policy recommendations.

Fifth, CMS acknowledges the importance of MLTSS programs offering a comprehensive service package to better coordinate care across LTSS, health, and behavioral health for people with disabilities. Study participants found it beneficial for the MCOs to hire people from the IDD field and develop IDD specific teams, in order to help the MCOs learn how address the complex health and LTSS needs of individuals with IDD. Additionally, state oversight in KanCare provided for continuity of care provisions for LTSS and targeted case management services so individuals with IDD and their families would not lose needed supports and services during the transition to MLTSS. Families having access to their existing Targeted Case Manager alongside the new MCO Care Coordinator to help with care coordination was necessary given the large caseloads of the MCO Care Coordination staff. Future MLTSS programs may consider limiting caseloads of Care Coordinators hired by MCOs so they have more time to establish relationships or consider a shared care coordination effort utilized in KanCare. Ensuring IDD competencies amongst MCOs and continuity of care provisions for services and care coordination could be considered in future MLTSS policy efforts.

The sixth recommendation from CMS involves ensuring a provider network to meet the needs of individuals with IDD. This was difficult to achieve in Kansas given the rural nature of the state and also providers at times selecting not to work with certain at-risk populations. This study was completed early in the implementation process and the MCOs were still actively working to enhance the provider network statewide. Rural states could look at ways to encourage large providers to expand their geographic scope. States could also include provisions in their MLTSS policy for provider training to encourage participation across all at-risk populations.

Finally, while not mentioned in the CMS proposed regulations, other groups have recommended recognizing and supporting the important role of family caregivers in MLTSS

(Consortium for Citizens with Disabilities, 2012; National Council on Disability, 2013). In this study, the family caregivers were found to still play a large role in the day-to-day support and decision making of their loved ones. Supporting family caregivers was identified as important, but there were no formal processes in place to pro-actively evaluate family caregiver needs. Future MLTSS policy could include recommendations to include family caregiver assessments as part of their MLTSS service delivery process.

Conclusion

This study's overall purpose was to describe the current implementation of MLTSS for adults with IDD and their family caregivers in Kansas. The specific aims included: 1) To understand the rationale behind and what happened with MLTSS implementation for adults with IDD in Kansas; 2) To understand how service coordination providers and family caregivers perceived care coordination and access to services for adults with IDD in MLTSS; 3) To understand how family caregivers and their roles were recognized in MLTSS for adults with IDD.

Regarding Aim One, the overall purpose of MLTSS for adults with IDD was to reduce costs while improving quality of care. Given the timing of the study, being one year into implementation, it was too soon to draw any conclusions regarding overall costs and quality changes. However, a key lesson learned was the amount of confusion and fear experienced by stakeholders, which could have been alleviated by taking more time to plan. Longer planning and implementation timelines would allow for more consideration of stakeholder feedback in the design of the MLTSS program. Further confirming these findings included stakeholder engagement and adequate planning are two provisions proposed in the new CMS proposed MLTSS regulations (Centers for Medicare and Medicaid Services, 2015).

Aim Two focused on the experiences of service coordination providers and families with access to services and care coordination in MLTSS. Improving access to services and coordinating care across health, behavior health, and LTSS are also highlighted in the CMS MLTSS rule changes (Centers for Medicare and Medicaid Services, 2015). Care coordination in MLTSS has been cited as a key mechanism by which MLTSS can improve quality of care, yet there are no standards established for best practices (Saucier & Burwell, 2015). In KanCare, a team-based method was utilized with the existing Targeted Case Manager and the MCO Care Coordinator working together. The team approach was helpful for continuity of care and maintaining established relationships with those familiar with the individual with IDD and their family caregiver. Since this study was completed early in the implementation process, study participants still reported experiencing role confusion and lack of clarity of ways to best solve problems with care access. Future MLTSS programs could consider including standards for care coordination including baseline qualifications, caseload size recommendations, and communication frequency expectations (Saucier & Burwell, 2015).

Establishing an extensive provider network also proved challenging in KanCare to date. The provider network is critical in order for individuals with IDD to have consumer choice and the ability to access needed services in a timely manner. Fortunately, KanCare included continuity of care provisions so no participants reported losing needed LTSS. However, they did report wait lists for dental services and DME providers had difficulty with timely payments. Provider education and capacity building will be important to develop a comprehensive provider network in future MLTSS programs for individuals with IDD. There are opportunities in MLTSS to address existing health disparities amongst individuals with IDD, but access to primary care

and preventive services through comprehensive provider networks will be required to achieve this goal.

Aim Three sought to understand how family caregivers of adults with IDD were acknowledged in their ongoing caregiving role as a part of MLTSS. Participants identified the critical role that family caregivers played, yet there were no formal processes in place to assess their ongoing needs. There is a need to include more formal assessments of family caregivers in MLTSS in order to help them find support options (Academy Health, 2015). A family caregiver assessment could include reviewing their well-being, discussing their changing support needs over time, and planning for future caregiving as the caregiver ages (Kelly et al., 2013; Williamson & Perkins, 2014). Beyond caregiver assessments, successful care coordination in MLTSS could also help alleviate some of the roles family caregiver play in decision-making (Naylor et al., 2015). There are also opportunities in MLTSS for providing caregiver education to help promote health promotion and wellness activities among individuals with IDD (Ervin et al., 2014).

Identifying means to address cost and quality in LTSS in the U.S. will remain a priority for states, as more of our population experiences disability due to longer life expectancies of adults with IDD and aging of the U.S. population. Furthermore, the ongoing reliance on family caregivers as needed partners in long-term care is also going to continue. The results of this study point to the benefits and challenges of utilizing a managed care approach to LTSS and also highlight best practices developed by CMS. At a minimum, future evaluations of MLTSS efforts for adults with IDD could include: reviewing care coordination best practices; identifying methods to enhance access to services; understanding best methods for stakeholder engagement; and acknowledging the critical role of the family caregiver.

REFERENCES

- Academy Health. (2015). *Measuring the quality of home-and-community-based services: A conversation about strategic directions for research and policy*. Paper presented at the Academy Health, Washington, DC.
- American Association on Intellectual and Developmental Disabilities. (2013). *Frequently asked questions on intellectual disability*. Retrieved from http://aaidd.org/intellectual-disability/definition/faqs-on-intellectual-disability#.Vcua_bclmZ0
- APS Healthcare Inc. (2005). *Family care independent assessment, an evaluation of access, quality and cost for calendar year 2003-2004*. Retrieved from <https://www.dhs.wisconsin.gov/sites/default/files/legacy/LTCare/pdf/FCIndepAssmt2005.pdf>
- Balbach, E. D. (1999). *Using case studies to do program evaluation*. Retrieved from <http://www.case.edu/affil/healthpromotion/ProgramEvaluation.pdf>
- Beange, H., Mcelduff, A., & Baker, W. (1995). Medical disorders of adults with mental retardation: A population study. *American Journal on Mental Retardation*, 99(6), 595-604.
- Bindman, A. B., Chattopadhyay, A., Osmond, D., Huen, W., & Baccetti, P. (2004). *Preventing unnecessary hospitalizations in Medi-Cal: Comparing fee-for-service with managed care*. Retrieved from http://www.chcf.org/~media/MEDIA_LIBRARY/Files/PDF/P/PDF/PreventableHospitalizationsInMediCal.pdf
- Bodde, A. E., & Seo, D. C. (2009). A review of social and environmental barriers to physical activity for adults with intellectual disabilities. *Disability and Health Journal*, 2(2), 57-66.
- Braddock, D., & Hemp, R. (2008). *Development of a family support services taxonomy*. Denver, CO: University of Colorado Denver School of Medicine's State of the States in Developmental Disabilities Project.

- Braddock, D., Hemp, R., Rizzolo, M. C., Tanis, E. S., Haffer, L., & Wu, J. (2015). *The state of the states in intellectual and developmental disabilities: Emerging from the great recession (Tenth ed.)*. Washington, DC: The American Association on Intellectual and Developmental Disabilities.
- Bronfenbrenner, U. (1979). *The ecology of human development*. Cambridge, MA: Harvard University Press.
- Brown, I., Parmenter, T. R., & Percy, M. (2007). Trends and issues in intellectual and developmental disabilities. In I. Brown & M. Percy (Eds.), *A comprehensive guide to intellectual and developmental disabilities* (pp. 45-58). Baltimore, MD: Brooks Publishing.
- Burns, M. (2009a). Medicaid managed care and cost containment in the adult disabled population. *Medical Care*, 47(10), 1069-1076.
- Burns, M. (2009b). Medicaid managed care and health care access for adult beneficiaries with disabilities. *Health Services Research*, 44(5), 1521-1541.
- Burwell, B., & Kasten, J. (2013). *Transitioning long term services and supports providers into managed care programs*. Retrieved from <http://www.medicaid.gov/medicaid-chip-program-information/by-topics/delivery-systems/downloads/transitioning-ltss.pdf>
- Caswell, K. J., & Long, S. K. (2015). The expanding role of managed care in the Medicaid program: implications for health care access, use, and expenditures for nonelderly adults. *The Journal of Health Care Organization, Provisions, and Financing*, 52, 1-7.
- Centers for Disease Control and Prevention. (2003). *Public health and aging: Trends in aging-United States and worldwide*. Retrieved from <http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5206a2.htm>
- Centers for Disease Control and Prevention. (2009). *U.S. surveillance of health of people with intellectual disabilities*. Retrieved from http://www.cdc.gov/ncbddd/disabilityandhealth/pdf/209537-A_IDmeeting_short_version12-14-09.pdf
- Centers for Medicare and Medicaid Services. (2013a). *CMS guidance for states using 1115 demonstrations or 1915(b) waivers for managed long term services and supports programs*. Retrieved from <http://www.medicaid.gov/Medicaid-CHIP-Program->

[Information/By-Topics/Delivery-Systems/Downloads/1115-and-1915b-MLTSS-guidance.pdf](http://www.cms.gov/Research-Statistics-Data-and-Systems/Statistics-Trends-and-Reports/NationalHealthExpendData/NHE-Fact-Sheet.html)

Centers for Medicare and Medicaid Services. (2013b). *Kansas section 1115 demonstration fact sheet*. Retrieved from <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Waivers/1115/downloads/ks/ks-kancare-fs.pdf>

Centers for Medicare and Medicaid Services. (2013c). *Long-term services and supports*. Retrieved from <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Supports/Long-Term-Services-and-Supports.html>

Centers for Medicare and Medicaid Services. (2013d). *NHE fact sheet*. Retrieved from <http://www.cms.gov/Research-Statistics-Data-and-Systems/Statistics-Trends-and-Reports/NationalHealthExpendData/NHE-Fact-Sheet.html>

Centers for Medicare and Medicaid Services. (2015). *Medicaid and CHIP managed care proposed rule CMS-2390-P*. Retrieved from <https://www.cms.gov/Newsroom/MediaReleaseDatabase/Fact-sheets/2015-Fact-sheets-items/2015-05-26.html>

Chaudry, R. V., Brandon, W. P., Thompson, C. R., Clayton, R. S., & Schoeps, N. B. (2003). Caring for patients under Medicaid mandatory managed care: Perspectives of primary care physicians. *Qualitative Health Research, 13*(37), 37-56.

Connolly, J., & Paradise, J. (2012). *People with disabilities and Medicaid managed care: Key issues to consider*. Retrieved from <http://kaiserfamilyfoundation.files.wordpress.com/2013/01/8278.pdf>

Consortium for Citizens with Disabilities. (2012). *Principles and recommendations for transitioning people with disabilities into Medicaid managed care*. Retrieved from http://c-c-d.org/task_forces/health/CCD_MMC_Principles_Shared_Document%28D0425203%29.pdf

Coppus, A. M. W. (2013). People with intellectual disability: What do we know about adulthood and life expectancy? *Developmental Disabilities Research Reviews, 18*(1), 6-16.

Corbin, S., Holder, M., & Engstrom, K. (2005). *Changing attitudes, changing the world: The health and health care of people with intellectual disabilities*. Washington, DC: Special Olympics International.

- Coughlin, T. A., Long, S. K., & Graves, J. A. (2008). Does managed care improve access to care for Medicaid beneficiaries with disabilities? A national study. *Inquiry*, 45(4), 395-407.
- Courtney-Long, E. A., Carroll, D. D., Zhang, Q. C., Stevens, A. C., Griffin-Blake, S., Armour, B. S., & Campbell, V. A. (2015). Prevalence of disability and disability type among adults United States, 2013. *Morbidity and Mortality Weekly Report*, 64(29), 777-783.
- Creswell, J. W., & Maietta, R. C. (2002). Qualitative research. In D. C. Miller & N. J. Salkind (Eds.), *Handbook of research design and social measurement, sixth edition* (pp.143-197). Thousand Oaks, CA: SAGE Publications, Inc.
- Croen, L. A., Zerbo, O., Ouan, Y., & Massolo, M. L. (2014, May). *Conditions among adults with ASD*. Paper presented at the International Society for Autism Research, Atlanta, GA.
- Crosby, R. A., DiClemente, R. J., & Salazar, L. F. (2006). Key steps in the research process. In R. A. Crosby, R. J. DiClemente & L. F. Salazar (Eds.), *Research methods in health promotion* (pp.3-22).. San Francisco, CA: Jossey-Bass.
- Deloitte. (2011). Kansas Medicaid: Design and implementation of a public input and stakeholder consult process. Retrieved from http://www.kdheks.gov/hcf/medicaid_reform_forum/download/KS_Public_Input_and_Stakeholder_Consult.pdf
- Dembner, A. (2012). *Putting consumers first. Promising practices for Medicaid managed long-term services and supports*. Retrieved from http://www.communitycatalyst.org/docstore/publications/putting_consumers_first_LTSSmanagedcare.pdf
- Drum, C. E. (2009). Models and approaches to disability. In C. E. Drum, G. L. Krahn & H. Bersani (Eds.), *Disability and public health* (pp. 27-44). Washington, DC: American Public Health Association.
- Duggan, M., & Hayford, T. (2013). Has the shift to managed care reduced Medicaid expenditures? Evidence from state and local-level mandate. *Journal of Policy Analysis and Management*, 32(2), 505-535.
- Eiken, S., Sredl, K., Gold, L., Kasten, J., Burwell, B., & Saucier, P. (2014, April 28, 2014). *Medicaid expenditures for long-term services and supports in FFY 2012*. Retrieved from <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Supports/Downloads/LTSS-Expenditures-2012.pdf>

- Ervin, D. A., Hennen, B., Merrick, J., & Morad, M. (2014). Healthcare for persons with intellectual and developmental disability in the community. *Frontiers in Public Health*, 2(83), 1-8.
- Factor, A., Heller, T., & M. Janicki. (2012). *Bridging the aging and developmental disabilities service networks: Challenges and best practice*. Retrieved from <http://www.rrtcadd.org/resources/Resources/Publications/Policy/Service/Briefs-&-Reports/Bridging-Report.pdf>
- Feinberg, L., & Houser, A. (2012). *Assessing family caregiver needs: Policy and practice considerations*. Washington, DC: AARP Public Policy Institute.
- Feinberg, L., Reinhard, S. C., Houser, A., & Choula, R. (2011). *Valuing the invaluable: 2011 update-the growing contributions and costs of family caregiving*. Retrieved from <http://www.aarp.org/relationships/caregiving/info-07-2011/valuing-the-invaluable.html>
- Gale, N. K., Heath, G., Cameron, E., Rashid, S., & Redwood, S. (2013). Using the framework method for analysis of qualitative data in multi-disciplinary health research. *BMC Medical Research Methodology*, 13(117), 1-8.
- Garrard, J. (2011). *Health sciences literature review made easy: The matrix method*. Sudbury, MA: Jones & Bartlett Learning.
- Gibson, M. J., Gregory, S. R., & Pandya, S. M. (2003). *Long-term care in developed nations: A brief overview*. Washington, DC: AARP Public Policy Institute.
- Gifford, K., Smith, V. K., Snipes, D., & Paradise, J. (2011). *A profile of Medicaid managed care programs in 2010: Findings from a 50-state survey*. Retrieved from <https://kaiserfamilyfoundation.files.wordpress.com/2013/01/8220-es.pdf>
- Glanz, K., & Bishop, D. B. (2010). The role of behavioral science theory in development and implementation of public health interventions. *Annual Reviews of Public Health*, 31, 399-418.
- Gold, M. (1999). Making Medicaid managed care research relevant. *Health Services Research*, 33(6), 1639-1649.
- Green, L. W., & Kreuter, M. (2005). *Health program planning: an educational and ecological approach* (4th ed.). New York, NY: McGraw-Hill.

- Guest, G., Bunce, A., & Johnson, L. (2006). How many interviews are enough? An experiment with data saturation and variability. *Field Methods*, 18(1), 59-82.
- Haley, W. E., & Perkins, E. A. (2004). Current status and future directions in family caregiving and aging people with intellectual disability. *Journal of Policy and Practice in Intellectual Disabilities*, 1(1), 24-30.
- Hall, J. P., Kurth, N. K., Chapman, S. L., & Shireman, T. I. (2015). Medicaid managed care: Issues for beneficiaries with disabilities. *Disability and Health Journal*, 8(1), 130-135.
- Head, M. J., & Conroy, J. W. (2005). Outcomes of self-determination in Michigan. In R. J. Stancliffe & K. C. Lakin (Eds.), *Costs and outcomes of community services for people with intellectual disabilities* (pp. 219-240). Baltimore, MD: Brooks Publishing.
- Hebbeler, K., Spiker, D., & Kahn, L. (2012). Individuals with disabilities education act's early childhood programs: Powerful vision and pesky details. *Topics in Early Childhood Special Education*, 31(4), 199-207.
- Hecht, E., & Reynolds, M. (2012). *Building a national agenda for supporting families with a member with intellectual and developmental disabilities*. Retrieved from [http://www.state.tn.us/cdd/documents/SUPPORTING FAMILIES Wingspread Document.pdf](http://www.state.tn.us/cdd/documents/SUPPORTING_FAMILIES_Wingspread_Document.pdf)
- Heller, T., & Factor, A. (2008). Family support and intergenerational caregiving: Report from the state of science in aging and developmental disabilities conference. *Disability and Health Journal*, 1(3), 131-135.
- Heller, T., Miller, A. B., & Hsieh, K. (1999). Impact of a consumer-directed family support program on adults with developmental disabilities and their family caregivers. *Family Relations*, 48(4), 419-427.
- Heller, T., Owen, R., & Crabb, C. (2015, June). *How are families involved in care of people with IDD enrolled in Medicaid managed care?* Poster presented at the American Association on Intellectual and Developmental Disabilities Conference, Louisville, KY.
- Heller, T., & Schindler, A. (2009). Family support interventions for families of adults with intellectual and developmental disabilities. In L. M. Glidden & M. M. Seltzer (Eds.), *International review of research in mental retardation* (Vol. 37, pp. 299-332). Washington, DC: Elsevier.

- Heller, T., & Sorensen, A. (2013). Promoting healthy aging in adults with developmental disabilities. *Developmental Disabilities Research Reviews*, 18(1), 22-30.
- Hensel, E., Rose, J., Kroese, B. S., & Banks-Smith, J. (2002). Subjective judgements of quality of life: A comparison study between people with intellectual disability and those without disability. *Journal of Intellectual Disability Research*, 46(2), 95-107.
- Hewitt, A., Agosta, J., Heller, T., Williams, A. C., & Reinke, J. (2013). Families of individuals with intellectual and developmental disabilities: Policy, funding, services, and experiences. *Intellectual and Developmental Disabilities*, 51(5), 349-359.
- Highsmith, K., & Somers, S. (2003). *Adults with disabilities in Medi-Cal managed care: Lessons from other states*. Retrieved from http://www.chcs.org/usr_doc/MediCalDisabilitiesLessons.pdf
- Ingram, C., Lind, A., & Ensslin, B. (2013). *Uniform assessment practices in Medicaid managed long-term services and supports program*. Retrieved from http://www.cdss.ca.gov/agedblinddisabled/res/CCI/chcs-uniform_assessment_mltss-9-12-13.pdf
- Janicki, M. P., Dalton, A. J., Henderson, C. M., & Davidson, P. W. (1999). Mortality and morbidity among older adults with intellectual disability: Health services considerations. *Disability Rehabilitation*, 21(5), 284-294.
- KanCare. (2014). *KanCare website*. Retrieved from <http://www.kancare.ks.gov/>
- Kansas Department for Aging and Disability Services. (2013). *IDD waiver consumer letter*. Retrieved from http://www.kancare.ks.gov/download/IDD_Waiver_Consumers_Letter.pdf
- Kansas Department of Health and Environment. (2013). *RE: Amendment to the KanCare Medicaid section 1115 demonstration, 11-W-00283/7*. Retrieved from <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Waivers/1115/downloads/ks/KanCare/ks-kancare-amend-req-ltr-08192013.pdf>
- Kansas Medicaid Workgroup. (2011). *Executive summary KanCare: Reinventing Medicaid for Kansas*. Retrieved from http://www.kancare.ks.gov/download/KanCare_Executive_Summary.pdf

- Kaskutas, L. A., Schmidt, L. A., Weisner, C., & Greenfield, K. (2000). Method for evaluating policy changes in alcohol services. *Addiction*, *95*(3), S329-345.
- Kastner, T. A., Walsh, K. K., & Criscione, T. (1997). Overview and implications of Medicaid managed care for people with developmental disabilities. *Mental Retardation*, *35*(4), 257-269.
- Kaye, H. S. (2014). Toward a model of long-term services and supports system: State policy elements. *The Gerontologist*, *54*(5), 754-761.
- Kaye, H. S., & Harrington, C. (2015). Long-term services and supports in the community: Towards a research agenda. *Disability and Health Journal*, *8*, 3-8.
- Kaye, H. S., Harrington, C., & LaPlante, M. P. (2010). Long-term care: Who gets it, who provides it, who pays, and how much? *Health Affairs*, *29*(1), 11-21.
- Kelly, K., Wolfe, N., Gibson, M. J., & Feinberg, L. (2013). *Listening to family caregivers: The need to include family caregiver assessment in Medicaid Home-and-Community-Based Service waiver programs*. Washington, DC: AARP.
- Kertroy, M. K., Russell, D. J., Rosenbaum, P., Jaffer, S., Law, M., McCauley, D., & Gorter, J. W. (2012). Development of an outcome measurement system for service planning for children and youth with special needs. *Child: Care, Health, and Development*, *39*(5), 750-759.
- Ko, M., Newcomer, R., Bindman, A.B., Kang, T., Hulett, D., & Spetz, J. (2015). *California's Medicaid personal care assistants: Characteristics and turnover among family and non-family caregivers*. Retrieved from http://healthworkforce.ucsf.edu/sites/healthworkforce.ucsf.edu/files/Report-Characteristics_and_Turnover_among_Family_and_Non-Family_Caregivers.pdf
- Krahn, G. L., & Drum, C. E. (2007). Translating policy principles into practice to improve health care access for adults with intellectual disabilities: A research review of the past decade. *Mental Retardation and Developmental Disabilities*, *13*(160-168).
- Krahn, G. L., Hammond, L., & Turner, A. (2006). A cascade of disparities: Health and health care access for people with intellectual disabilities. *Mental Retardation and Developmental Disabilities*, *12*, 70-82.

- Krahn, G. L., Walker, D. K., & Correa-De-Araujo, R. (2015). Persons with disabilities as unrecognized health disparity population. *Journal of Public Health, 105*(S2), S198-206.
- Kronick, R. G., Bella, M., & Gilmore, T. P. (2009). *The faces of Medicaid III: Refining the portrait of people with multiple chronic conditions*. Trenton, NJ: Center for Health Care Strategies, Inc.
- Lachapelle, Y., Wehmeyer, M. L., Haelewyck, M. C., Courbois, Y., Keith, K. D., Schalock, R., . . . Walsh, P.N. (2005). The relationship between quality of life and self-determination: an international study. *Journal of Intellectual Disability Research, 49*(10), 740-744.
- Laragy, C., & Ottmann, G. (2011). Towards a framework for implementing individual funding based on an Australian case study. *Journal of Policy and Practice in Intellectual Disabilities, 8*(1), 18-27.
- Larson, S. A., Hewitt, A. S., & Lakin, K. C. (2004). Multiperspective analysis of workforce challenges and their effects on consumer and family quality of life. *American Journal on Mental Retardation, 106*(6), 481-500.
- Larson, S. A., Ryan, A., Salmi, P., Smith, D., & Wuorio, A. (2012). *Residential services for persons with developmental disabilities: Status and trends through 2011*. Minneapolis, MN: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.
- Lewin Group. (2009). *Medicaid managed care cost savings-a synthesis of 24 studies*. Retrieved from [http://leg.mt.gov/content/Committees/Interim/2011-2012/Children-Family/Topics/Medicaid Monitoring/lewin-synthesis-of-managed-care-studies.pdf](http://leg.mt.gov/content/Committees/Interim/2011-2012/Children-Family/Topics/Medicaid%20Monitoring/lewin-synthesis-of-managed-care-studies.pdf)
- Lewis, M. A., Lewis, C. E., Leake, B., King, B. H., & Lindemann, R. (2002). The quality of health care for adults with developmental disabilities. *Public Health Reports, 117*(2), 174-184.
- Marshall, B., Cardon, P., Poddar, A., & Fontenot, R. (2013). Does sample size matter in qualitative research?: A review of qualitative interviews in IS research. *Journal of Computer Information Systems, 54*(1), 11-22.
- Marso, A. (2014, March 29). State agency, disability rights center at odds, *The Topeka Capital-Journal*. Retrieved from <http://cjonline.com/news/2014-03-29/state-agency-disability-rights-center-odds>

- McDonnell, D. D., & Graham, C. L. (2015). Medicaid beneficiaries in California reported less positive experiences when assigned to a managed care plan. *Health Affairs*, 34(3), 447-454.
- Merten, J., Pomeranz, J. L., King, J. L., Moorhouse, M., & Wynn, R. D. (2015). Barriers to cancer screening for people with disabilities: A literature review. *Disability and Health Journal*(8), 9-16.
- Morstad, D. (2012). *How prevalent are intellectual and developmental disabilities in the United States?* Retrieved from <http://bethesda institute.org/document.doc?id=413>
- National Alliance for Caregiving. (2015). *Caregiving in the U.S.* Washington, DC.
- National Association of States United for Aging and Disabilities. (2014). *State Medicaid integration tracker, September 1, 2014.* Retrieved from http://nasuad.org/sites/nasuad/files/September Tracker - Final Version_0.pdf
- National Association of States United for Aging and Disabilities. (2015). *State Medicaid integration tracker, July 20, 2015.* Retrieved from <http://www.nasuad.org/sites/nasuad/files/July%202015%20Tracker%20-%20final.pdf>
- National Council on Disability. (2004). *Consumer-directed health care: How well does it work?* Retrieved from <http://www.ncd.gov/publications/2004/Oct262004>
- National Council on Disability. (2009). The current state of health care for people with disabilities. Retrieved from <http://www.ncd.gov/publications/2009/Sept302009>
- National Council on Disability. (2013). *Medicaid managed care for people with disabilities.* Retrieved from <http://www.ncd.gov/publications/2013/20130315/>
- National Council on Disability. (2014a). *Part I summary: Medicaid managed care forum.* Retrieved from <http://www.ncd.gov/publications/2014/11042014/>
- National Council on Disability. (2014b). Re: Amendment to KanCare Medicaid section 1115 follow-up. Retrieved from http://media.khi.org/news/documents/2014/01/14/CMS_KanCare_Letter_Follow_Up.pdf

- Naylor, E. T., Kurtzman, E. T., Miller, E. A., Nadash, P., & Fitzgerald, P. (2015). An assessment of state-led reform of long-term services and supports. *Journal of Health Politics, Policy, and Law*, 40(3), 531-574.
- Nonnemacher, S. L., & Bambara, L. M. (2011). "I'm supposed to be in charge": self-advocates' perspectives on their self-determination support needs. *Intellectual and Developmental Disabilities*, 49(5), 327-340.
- O'Keefe, J., Saucier, P., Jackson, B., Cooper, R., McKenney, E., Crisp, S., & Moseley, C. (2010). *Understanding Medicaid home and community services: A Primer, 2010 Edition*. Washington, DC: U.S. Department of Health and Human Services.
- Office of Inspector General. (2014). *Access to care: Provider availability in Medicaid managed care*. (OEI-02-13-00670). Washington, DC: Department of Health and Human Services Retrieved from <http://oig.hhs.gov/oei/reports/oei-02-13-00670.pdf>.
- Owen, R., Crabb, C., & Heller, T. (2015, June). *Health status and caregiving appraisal of family members of people with IDD*. Poster presented at the American Association on Intellectual and Developmental Disabilities Conference, Louisville, KY.
- Parish, S. L., & Huh, J. (2006). Health care for women with disabilities: Population-based evidence of disparities. *Health and Social Work*, 31(1), 7-15.
- Parish, S. L., & Saville, A. W. (2006). Women with cognitive limitations in the community: Evidence of disability-based disparities in health care. *Mental Retardation*, 44(4), 249-259.
- Perkins, E. A., & Berkman, K. A. (2012). Into the unknown: Aging with Autism Spectrum Disorders. *American Journal on Intellectual and Developmental Disabilities*, 117(6), 478-496.
- Perkins, E. A., & Haley, W. E. (2010). Compound caregiving: When lifelong caregivers undertake additional caregiving roles. *Rehabilitation Psychology*, 55(4), 409-417.
- Perkins, E. A., & Moran, J. A. (2010). Aging adults with intellectual disabilities. *Journal of the American Medical Association*, 304(1), 91-92.
- Peterson, L. J., & Hyer, K. (2015). Shifting to Medicaid managed long-term care: Are vulnerable beneficiaries properly informed? *Journal of Applied Gerontology*, 1-18.

- Pope, C., Ziebland, S., & Mays, N. (2000). Qualitative research in health care analyzing qualitative data. *BMJ*, *320*, 114-116.
- Premo, B., Kailes, J. I., Schwier, E., & Richards, C. (2003). *Adults with disabilities in Medi-Cal: The beneficiary perspective*. Retrieved from http://www.chcf.org/~media/MEDIA_LIBRARY/Files/PDF/M/PDF_MediCalDisabilitiesBeneficiaries.pdf
- President's Committee for People with Intellectual Disabilities. (2012). *Managed long-term services and supports*. Retrieved from http://www.acl.gov/NewsRoom/Publications/docs/PCPID_FullReport2012.pdf
- QSR International. (2014). *NVivo 10*. Retrieved from http://www.qsrinternational.com/products_nvivo.aspx
- Reaves, E. L., & Musumeci, M. (2015). *Medicaid and long-term services and supports: A primer*. Washington, DC: Kaiser Family Foundation.
- Reinhard, S. C., Kassner, E., Houser, A., Ujvari, K., Mollica, R., & Hendrickson, L. (2014). *Raising expectations: A state scorecard on long-term services and supports for older adults, people with physical disabilities, and family caregivers* (Second Edition ed.). Washington, DC: AARP.
- Rimmer, J. H., & Yamaki, K. (2006). Obesity and intellectual disability. *Mental Retardation and Developmental Disabilities Research Reviews*, *12*(1), 22-27.
- Saucier, P., & Burwell, B. (2015). *Care coordination in managed long-term services and supports*. Ann Arbor, MI: Truven Health Analytics and AARP Public Policy Institute.
- Saucier, P., Kasten, J., Burwell, B., & Gold, L. (2012). *The growth of managed long-term services and supports (MLTSS) programs: A 2012 update*. Retrieved from http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Delivery-Systems/Downloads/MLTSSP_White_paper_combined.pdf
- Schalock, R., & Alonso, M. A. V. (2002a). Family-centered quality of life. In D. L. Braddock (Ed.), *Handbook on quality of life for human service practitioners* (pp. 165-180). Washington, DC: Association on Mental Retardation.
- Schalock, R., & Alonso, M. A. V. (2002b). Organizational-Level Application of the Concept of Quality of Life. In D. L. Braddock (Ed.), *Handbook on quality of life for human service*

- practitioners* (pp. 309-330). Washington, DC: American Association on Mental Retardation.
- Shogren, K. A., & Broussard, R. (2011). Exploring the perceptions of self-determination of individuals with intellectual disability. *Intellectual and Developmental Disabilities, 49*(2), 86-102.
- Shogren, K. A., Wehmeyer, M. L., Reese, R. M., & O'Hara, D. (2006). Promoting self-determination in health and medical care: A critical component of addressing health disparities in people with intellectual disabilities. *Journal of Policy and Practice in Intellectual Disabilities, 3*(2), 105-113.
- Silverman, M., Ricci, E. M., & Gunter, M. J. (1990). Strategies for increasing the rigor of qualitative methods in evaluation of health care programs. *Evaluation Review, 14*, 57-74.
- Stokols, D. (1992). Establishing and maintaining healthy environments: Towards a social ecology of health promotion. *American Psychologist, 47*, 6-22.
- Substance Abuse and Mental Health Services Administration. (2011). *Leading change: A plan for SAMHSA's roles and actions 2011-2014*. Retrieved from <https://store.samhsa.gov/shin/content/SMA11-4629/01-FullDocument.pdf>
- Summer, L. (2011). *Examining Medicaid managed long-term service and support programs: Key issues to consider*. Retrieved from <http://www.kff.org/medicaid/8243.cfm>
- Thomas, R., & Barnes, M. (2010). Life expectancy for people with disabilities. *NeuroRehabilitation, 27*, 201-209.
- Ticha, R., Lakin, K. C., Larson, S. A., Stancliffe, R. J., Taub, S., Engler, J., . . . Moseley, C. (2012). Correlates of everyday choice and support-related choice for 8,892 randomly sampled adults with intellectual and developmental disabilities in 19 states. *Intellectual and Developmental Disabilities, 50*(6), 486-504.
- Truven Health Analytics. (2013). *Timeline for developing a managed long term services and supports program*. Retrieved from <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Delivery-Systems/Downloads/MLTSS-Timeline.pdf>

- Turnbull, H. F., Beegle, G., & Stowe, M. J. (2001). The core concepts of disability policy affecting families who have children with disabilities. *Journal of Disability Policy Studies, 12*, 133-143.
- U.S. Department of Health and Human Services. (2002). *Closing the gap: A national blueprint to improve the health of persons with mental retardation*. Washington, DC: Surgeon General's Conference on Health Disparities and Mental Retardation.
- U.S. Department of Health and Human Services. (2005). *The Surgeon General's call to action to improve the health and wellness of persons with disabilities*. Washington, DC: Office of the Surgeon General.
- U.S. Department of Health and Human Services. (2015). *Healthy People 2020 disability and health objectives*. Retrieved from <http://www.healthypeople.gov/2020/topics-objectives/topic/disability-and-health/objectives>
- U.S. Senate Commission on Long-Term Care. (2013). *Report to Congress*. Retrieved from <http://www.gpo.gov/fdsys/pkg/GPO-LTCCOMMISSION/pdf/GPO-LTCCOMMISSION.pdf>
- United Nations. (2006). *Convention on the rights of persons with disabilities*. Retrieved from <http://www.un.org/disabilities/convention/conventionfull.shtml>
- University of Minnesota. (2006). *Family support services in the United States*. Retrieved from <http://ici.umn.edu/products/prb/171/171.pdf>
- Wegman, M. P., Herndon, J. B., Muller, K. E., Graham, G. N., Bogel, W. B., Case, K. H., . . . Shenkman, E.A. (2015). Quality of care for chronic conditions among disabled Medicaid enrollees. *Medical Care, 53*(7), 599-606.
- Wehmeyer, M., Bersani, H., & Gagne, R. (2000). Riding the third wave: Self-determination and self-advocacy in the 21st century. *Focus on Autism & Other Developmental Disabilities, 15*(2), 106-115.
- Wehmeyer, M. L., & Bolding, N. (2001). Enhanced self-determination of adults with intellectual disability as an outcome of moving to community-based work or living environment. *Journal of Intellectual Disability Research, 45*(5), 371-383.

- Williamson, H. J., & Perkins, E. A. (2014). Family caregivers of adults with intellectual and developmental disabilities: Outcomes associated with U.S. services and supports. *Intellectual and Developmental Disabilities, 52*(2), 147-159.
- Williamson, H.J., Perkins, E.A., Acosta, A., Fitzgerald, M., Agrawal, J., & Massey, O.T. (in review). Family caregivers of individuals with intellectual and developmental disabilities: Experiences with Medicaid managed care long-term services and supports in the United States.
- Yin, R. K. (2014). *Case study research: Design and methods*. (5th ed.) Thousand Oaks, CA: SAGE Publications, Inc.
- Zuna, N., Summers, J. A., Turnbull, A. P., Hu, X., & Xu, X. (2011). Theorizing about family quality of life, value of a theory of family quality of life. In R. Kober (Ed.), *Enhancing the quality of life of people with intellectual disabilities* (pp. 241-278). New York, NY: Springer.

APPENDICES TITLE PAGE

APPENDIX A: LITERATURE REVIEW

Intellectual and/or Developmental Disabilities Prevalence and Definition

The field of public health has a role to enhance the health, wellness, and quality of life of individuals with disabilities (Drum, 2009). Recent estimates from the Centers for Disease Control and Prevention found that 22% of adults in the United States report some type of disability (Courtney-Long et. al., 2015). The prevalence of individuals with intellectual and/or developmental disabilities (IDD) is estimated to be around 1.5 to 2.5% of the total United States population or approximately 4.6 to 7.7 million individuals (Morstad, 2012). The prevalence of IDD is estimated, due to differing definitions of the term IDD over time and lack of consistency in surveillance efforts regarding individuals with IDD (Hewitt et al., 2013).

The American Association on Intellectual and Developmental Disabilities (2013) defines an intellectual disability as a disability that must originate before age 18 and involves having a limitation in both intellectual functioning and adaptive behaviors (social and practical skills). A developmental disability must originate before age 22 and can include a cognitive impairment or physical impairment or both. Developmental disability is an umbrella term that includes intellectual disabilities and they are typically combined into one group. Therefore, in practice, the terms are combined into one grouping including intellectual and/or developmental disabilities (IDD).

Health Disparities and Comorbidity

Individuals with IDD have complex needs complicated by comorbid conditions and health disparities. Individuals with IDD experience poorer health than the general population with higher rates of hearing loss, vision loss, cardiovascular disease, obesity, respiratory disease, mental health conditions, diabetes, high cholesterol, high blood pressure, and poor oral health

(Beange et al., 1995; Corbin et al., 2005; Croen et al., 2014; Hensel et al., 2002; Krahn et al., 2006; Krahn et al., 2015; Merten et al., 2015; National Council on Disability, 2009, 2013). It is a combination of factors that influence health disparities experienced by people with IDD including secondary conditions associated with genetic disorders, lower socioeconomic status, social isolation, poor oral health, poor nutrition, inadequate health education, and lack of access to health care (Krahn et al., 2006).

Individuals with IDD are also more likely to poorly manage chronic conditions (Centers for Disease Control and Prevention, 2009). Individuals with IDD are less likely to participate in physical activity due to transportation difficulty, lack of financial resources, and limited awareness about options for physical activity (Bodde & Seo, 2009). Individuals with IDD residing in family homes are less likely to be physically active or to receive preventative care resulting in higher obesity rates compared to those living in group residences (Lewis, Lewis, Leake, King, & Lindemann, 2002; Rimmer & Yamaki, 2006). Women with IDD are less likely to receive screenings and more likely to postpone needed care as compared to women without disabilities (Parish & Huh, 2006; Parish & Saville, 2006). Clearly, people with IDD need more education on managing their health and wellness (Shogren et al., 2006). A review of research on health promotion and adults with IDD found that screenings, health promotion interventions, health education, and physical activity encouragement are found to be effective in improving health behaviors for adults with IDD (Heller & Sorensen, 2013).

Health disparities among individuals with IDD are further compounded by their already limited access to health providers with expertise in meeting the needs of the IDD population (Krahn et al., 2006). Lack of health provider training on IDD also results in difficulty maintaining continuity of care and with the identification of health and mental health conditions

(Krahn et al., 2006). There is limited exposure to providing care for individuals with IDD in existing guidelines for training health professionals (Krahn & Drum, 2007). In a survey of United States medical schools and dental schools, half of the medical and dental school administrators report their graduates lack competency to treat individuals with IDD (Corbin et al., 2005). However, there is interest in expanding the curriculum to include the needs of the IDD population and a majority of the administrators indicate that they would implement an IDD curriculum if given one (Corbin et al., 2005).

To address these health disparities, the U.S Surgeon General recognizes that individuals with IDD need to be equal partners in decision making with health care providers (U.S. Department of Health and Human Services, 2002). In two seminal reports, the U.S. Surgeon General developed a blueprint and identified goals to improve the health and wellness of people with IDD (U.S. Department of Health and Human Services, 2002, 2005). There is an ongoing need to increase knowledge and understanding of individuals with IDD in order to improve their health care and to provide more opportunities for health promotion in the community (U.S. Department of Health and Human Services, 2002, 2005). In order to achieve these goals, providers need training on working respectfully with people with IDD and services and supports need to be made more accessible (U.S. Department of Health and Human Services, 2002, 2005). Finally, the financing of health care for individuals with IDD needs to be carefully monitored and evaluated to identify models and processes to produce positive health and wellness outcomes (U.S. Department of Health and Human Services, 2002, 2005).

Self-Determination and Self-Advocacy

The National Council on Disability (2004) identifies self-determination as positively impacting health and wellness outcomes for individuals with IDD. In addition, self-

determination and self-advocacy for adults with IDD have been found enhance consumer choice, improve quality of life, reduce unmet needs, increase satisfaction with services, and reduce the desire for out-of-home placement (Head & Conroy, 2005; Heller et al., 1999). Self-determination is a core domain of quality of life for individuals with IDD (Lachapelle et al., 2005; Schalock & Alonso, 2002b; Shogren et al., 2006). Therefore, self-determination and self-advocacy are now guiding philosophies in the design of supports and services for people with IDD.

Self-determination is defined by self-advocates and is reflected in existing disability policy. Self-advocates, or individuals with IDD, define self-determination as speaking on their own behalf and being in charge (Nonnemacher & Bambara, 2011). In addition, self-advocates identify self-determination as not only being able to make day-to-day choices, but also being able to make complex choices about their life goals regarding where they work, where they live, and with whom they spend their time (Shogren & Broussard, 2011). In a review of existing disability policy, aspects of self-determination including empowerment, autonomy, and participation in decision-making, are reflected as core concepts across disability policies (Turnbull, Beegle, & Stowe, 2001).

The self-determination and self-advocacy movements for individuals with IDD began in the 1970s and 1980s. Since that time, there has been increasing acknowledgement that as individuals with IDD mature into adulthood, they deserve the right to make their own choices and to speak for themselves (Wehmeyer, Bersani, & Gagne, 2000). The self-advocacy movement was born out of the idea that people with IDD need to have a voice in the type of lives they want to live, and the impact of this movement is evidenced by individuals with IDD marrying, having children, working, and experiencing more independent living (Brown, Parmenter, & Percy, 2007).

Self-determination is further encouraged by the shift in prioritizing services and supports from institutional to home and community based services (HCBS) following the Olmstead decision in 1999 which ensured that individuals with disabilities would not be unjustly segregated to institutional settings (O'Keefe et al., 2010; Shogren et al., 2006). In the design of HCBS, self-determination is defined as individuals with IDD having the authority to manage their own lives and to manage the supports and services necessary to meet their life goals (O'Keefe et al., 2010).

Longer Life Expectancy and Aging U.S. Population

Due to existing health disparities, individuals with IDD do not share the same life expectancy as the general population, however, changes like the move to more community-based care and increased self-determination have meant that life expectancies for individuals with IDD have been increasing over time (Coppus, 2013; Factor et al., 2012; Thomas & Barnes, 2010). Given the longer life expectancies, it will be imperative to improve health care professionals' and service providers' understanding of the needs of adults with IDD not only with regard to present needs but also how these needs will change as the aging process occurs (Janicki, Dalton, Henderson, & Davidson, 1999; Perkins & Berkman, 2012; Perkins & Moran, 2010). Additionally, there is a demographic shift occurring in the United States. It is estimated that the proportion of individuals ages 65 and older in the U.S. will increase from 12.4% in 2000 to 19.6% by 2030, and the growing aging population is likely to experience chronic illness and disability (Centers for Disease Control and Prevention, 2003). Given our aging demographics and longer life expectancies of individuals with IDD, our systems of care will likely see an increase in demand for disability-related supports and services and support from family caregivers.

Family Caregivers

Our public health and behavioral health systems will also need to be responsive to the needs of family caregivers who often play a significant role in the lives of individuals with IDD. A report from the United States Senate Commission on Long-Term Care (2013), estimated that in 2009 there were 62 million family caregivers providing care to a loved one in need. The unpaid efforts of family caregivers was estimated to be worth \$450 billion in 2009, more than annual expenditures on Medicaid long-term services and supports (LTSS) which was \$125 billion in 2011 (Centers for Medicare and Medicaid Services, 2013c; Feinberg, Reinhard, Houser, & Choula, 2011).

Approximately 71% of individuals with IDD continue to live with and be supported by a family caregiver and this is likely to continue due more community-based care and long wait-lists for out-of-home care (Braddock et al., 2015; Heller & Schindler, 2009). There has been an almost four fold increase in the number of people with IDD living with family members between 2000 and 2011 and this co-residence results in family caregivers providing the bulk of the daily supports (Kaye et al., 2010; Larson et al., 2012). A shortage of living options and availability of support staff means that the reliance on family caregivers is likely to continue (National Council on Disability, 2013). In one evaluation of Medicaid personal care assistance services, it was found that employing family caregivers as paid personal care assistance resulted in less turnover and more continuity of care (Ko et al., 2015).

Self-advocacy and self-determination in decision-making for adults with IDD is paramount, yet some adults with IDD often have an ongoing need for family caregiver support in their decision-making (Heller & Factor, 2008). People with IDD can invite others in their lives, such as family and friends, to assist them in directing and managing their services and supports

(O'Keefe et al., 2010). If an individual has a legal guardian or surrogate decision maker, it is expected that the guardian will uphold the wishes of the individual with IDD (O'Keefe et al., 2010). However, conflict exists in the disability field regarding the role of family members in decision-making regarding services and supports (Hewitt et al., 2013). Some in the disability field think the family perspective should not be included because it can reduce the level of self-determination (Hewitt et al., 2013). Meanwhile others, including self-advocates, note that they still need the support of their family to help with decisions and don't feel that family caregiver influence takes away from their self-determination (Hewitt et al., 2013).

Family caregivers of adults with IDD are unique from other caregivers in that their role is typically a lifelong endeavor (Haley & Perkins, 2004). In addition, family caregivers of adults with IDD can become "compound caregivers" providing care for their adult son or daughter with and IDD and other family members who develop care needs over time (Perkins & Haley, 2010). A systematic literature review identified that family caregivers of adults with IDD in the U.S. experience economic, mental health, and physical health outcomes associated with their caregiving role (Williamson & Perkins, 2014). Our existing systems of care for adults with IDD rely heavily on family caregivers, and it will be important to monitor caregiver needs over time so family caregivers can maintain their caregiving role.

Family caregivers play a critical role in our systems of care for adults with IDD but challenges remain in providing supports and services to meet the needs of the family caregiver. A particular challenge is the lack of consensus on the definition of family support services (Hewitt et al., 2013). A group of national experts, including family caregivers and self-advocates, convened at the Wingspread conference in 2011 and developed consensus on a definition that identified family support services as being services which are designed to benefit the family unit

with the ultimate goal to benefit the individuals with IDD (Hecht & Reynolds, 2012). Examples of family support services are care coordination, respite, cash assistance, and home modifications (Hecht & Reynolds, 2012). Family support services are important for reducing stress, reducing out-of-pocket spending to provide care in the home, allowing family members to maintain employment, and reducing the likelihood for institutional placement (Hewitt et al., 2013).

Despite this growing reliance on family caregivers and the promise of providing family support services, in 2013, only 6.7% of spending on LTSS was spent on supporting family caregivers (Braddock et al., 2015). This is in part due the person-centered focus of existing supports and service systems for adults with IDD. The person-centered planning approach involves the individual with IDD identifying priorities and goals and the supports and services needed to achieve these goals (National Council on Disability, 2013).

In order to better support family caregivers, the use of both a person-centered and family-centered approach is recommended where the goals of the individual with IDD are honored while also building up their existing support network (Kelly et al., 2013; National Council on Disability, 2013). In a family-centered approach, the goals of the individual with IDD are honored while also addressing the needs of their family caregiver (National Council on Disability, 2013). Family-centered care is important as family caregivers play a vital partnership role with formal support systems serving as “field experts” needed to ensure system success (Hewitt et al., 2013).

Supports and Services for Adults with IDD

Adults with IDD have multifaceted needs that are being met through the support of family caregivers and Medicaid funded services and supports. Medicaid is the primary funding source for individuals with disabilities and this group has the highest spending per capita of any

Medicaid group, making up 15% of all beneficiaries but spending 42% of all Medicaid dollars (Connolly & Paradise, 2012). Medicaid covers a broad range of services including traditional medical services and long-term services and supports (LTSS), and it is estimated that in 2008, 41% of Medicaid spending for individuals with disabilities was for LTSS (Connolly & Paradise, 2012).

Home and community-based services (HCBS) are primarily funded through Medicaid and are designed to provide an alternative to institutional care for adults with IDD, and 70% of LTSS spending for adults with IDD was dedicated to HCBS in 2012 (Eiken et al., 2014; O'Keefe et al., 2010). Home and community-based services include a wide range of community-based LTSS including: habilitation, personal assistance services, family support, transportation, supported employment, supported living, assistive technology, and home modifications (Braddock et al., 2015). Long-term services and supports can also cover costs associated with nursing homes and intermediate care facilities (Braddock et al., 2015). Medicaid LTSS costs rose from \$93 billion in 2002 to \$125 billion in 2011 and are anticipated to continue increasing, due, in part, to the longer life expectancies of individuals with IDD (Braddock et al., 2015; Centers for Medicare and Medicaid Services, 2013d).

Managed Care Long-term Services and Supports (MLTSS)

Given the aging of the U.S. population, longer life expectancies of individuals with IDD, and the complex needs of individuals with IDD resulting in elevated and increasing Medicaid costs, there is a growing trend towards managed care for LTSS (MLTSS) (President's Committee for People with Intellectual Disabilities, 2012; Saucier et al., 2012). Managed care can be traced back to the 1930s and has grown over time in the financing of health care service (National Council on Disability, 2013). Providing LTSS in a fee-for-service model can result in

poor coordination of services and increased expenditures (President's Committee for People with Intellectual Disabilities, 2012). Medicaid managed care LTSS (MLTSS) holds promise to control costs while improving quality of care and more states are moving towards utilizing MLTSS for adults with IDD (Gifford et al., 2011). States have more experience with managed care for behavioral health and health care services, but adults with IDD had been excluded in most states until recent years due to their complex needs (Centers for Medicare and Medicaid Services, 2013a).

There is great variety in the design and implementation of managed care programs including their financial and corporate structure, geographic reach, type of enrollment, level of stakeholder engagement, and scope of services (National Council on Disability, 2013). There are three main financial structures seen in managed care including risk-based managed care organizations (MCOs), primary case management, and non-comprehensive pre-paid health plans (National Council on Disability, 2013). The risk-based MCOs model is the model utilized with the move from fee-for-service LTSS to MLTSS (President's Committee for People with Intellectual Disabilities, 2012). In the risk-based model, states contract with MCOs on a capitated or per-member-per-month payment system to provide services to Medicaid enrollees (Summer, 2011). The MCO takes on the risk because if they provide services below the capitated payment, then they make a profit, but if they provide services above the capitated payment they risk taking a financial loss (President's Committee for People with Intellectual Disabilities, 2012). The MCO is responsible for providing case management and providing a network of available providers to enrollees (President's Committee for People with Intellectual Disabilities, 2012). Managed care organizations can differ in their corporate structure as well including non-profit,

government, or private for-profit commercial entities as the main three corporate structures (Summer, 2011).

Additionally, there is diversity in the geographic reach, types of enrollment options, and level of stakeholder engagement in MLTSS. In some states, their MLTSS program is limited to a few counties, some roll out the program regionally over time, and some choose to implement statewide (Saucier et al., 2012). States can also determine if their MLTSS program will require voluntary enrollment, mandatory enrollment, or a mandatory enrollment with an opt-out provision (National Council on Disability, 2013). Mandatory enrollment means that those in the designated populations must enroll in MLTSS and mandatory with an opt-out means they must enroll for at least a period of time before deciding to opt-out of MLTSS. Finally, voluntary enrollment indicates that individuals with IDD must volunteer to enroll in MLTSS, but they can also choose to stay with current fee-for-service LTSS. Stakeholder engagement is necessary in the design and implementation of MLTSS and states have flexibility in mechanisms selected to engage stakeholders (President's Committee for People with Intellectual Disabilities, 2012). Common types of stakeholder engagement can include convening an advisory committee including individuals with IDD and family caregivers and having members complete an annual survey about satisfaction with supports and services (Saucier et al., 2012).

Finally, MLTSS programs can vary in the scope of services included under the management of their MCOs. States can choose to integrate all health, behavioral health, pharmacy, and HCBS under their MCOs or they can choose to cover a more limited scope of services and supports (Saucier et al., 2012). As of 2012, only two states had fully integrated programs for adults with IDD, Arizona and Wisconsin, covering health, behavioral health, pharmacy, and HCBS in MLTSS (Saucier et al., 2012).

The diversity in options for implementing MLTSS creates added complexity on drawing conclusions about MLTSS's influence on quality and cost of care (Connolly & Paradise, 2012). The evidence that does exist about managed care for people with disabilities is mixed and is also limited to a primary focus on health care services rather than LTSS (Burns, 2009b; Duggan & Hayford, 2013). Reviews of national data from 1996-2004 on health care access and preventative care use for adults age 18-64 with a disability found a decrease in access to specialists for MCO enrollees versus fee-for-service and no differences in monthly costs for those in fee-for-service counties or managed care counties (Burns, 2009b). Adults with disabilities in urban areas found better access to care under managed care policies but those in rural areas did not (Coughlin et al., 2008). A qualitative evaluation of a state program found that Medicaid enrollees with disabilities (including both fee-for-service and managed care) had difficulty locating specialists including psychiatric care (Premo et al., 2003). A state specific evaluation found reduced average annual preventable hospitalization rates by 25% for adults with disabilities (Bindman et al., 2004). A report synthesizing the influence of managed care on costs found savings from one to twenty percent primarily due to decreases in inpatient care and reduced pharmacy costs (Lewin Group, 2009).

While there is some information about managed care's influence on health care costs and utilization, very little is known about MLTSS. One reason for the limited information is due to the small proportion of LTSS, only six percent in 2012, provided under managed care (Eiken et al., 2014). The limited scope of information on individuals with IDD in MLTSS can be attributed to the small proportion of people with IDD enrolled in MLTSS, approximately 10% or 135,000 people in 2012 (Saucier et al., 2012).

States moving to MLTSS should not expect to see cost savings in the short term and there is mixed evidence on actual cost savings over time (Dembner, 2012; Summer, 2011). An evaluation of Wisconsin's MLTSS program, comparing individuals enrolled in MLTSS to those in fee-for-service LTSS, saw cost savings for individuals with physical disabilities and aging adults, but did not find cost savings for adults with IDD (APS Healthcare Inc. , 2005). A benefit of moving to MLTSS could be reduction in waiting lists for services, but evidence is not conclusive on MLTSS's influence on improving outcomes for consumers (APS Healthcare Inc. , 2005; Summer, 2011). Some states using MLTSS report expanding eligibility to meet unmet needs, adding new service offerings, shifting more people away from institutional care, and improving the ease of state budget planning (Dembner, 2012).

Despite the mixed evidence regarding the ability of MLTSS to reduce costs and improve care, more states are moving towards MLTSS for adults with IDD. Arizona has offered all Medicaid funded programs in a managed care model since their inception of Medicaid in 1987, so they are the first state to utilize MLTSS for individuals with IDD (National Council on Disability, 2013). Across all populations, the growth of MLTSS doubled from eight states in 2004 to 16 states in 2012 (Saucier et al., 2012). In 2012, only seven states (AZ, DE, HI, MI, NC, PA, WI) included individuals with IDD in MLTSS, six states moved to MLTSS for IDD between 2012 to present (FL, IL, KS, NJ, NY, TX), and four states (LA, NE, NH, TN) are planning to convert to MLTSS in the next few years (National Association of States United for Aging and Disabilities, 2015; Saucier et al., 2012). There are growing concerns from the IDD community about the rapid growth of MLTSS for adults with IDD due to inconclusive evidence regarding outcomes to date.

Concerns about MLTSS

A primary concern within the IDD community is that MLTSS will lead to decreased access to services (President's Committee for People with Intellectual Disabilities, 2012). In order for MLTSS to be successful there needs to be an adequate LTSS workforce available to meet consumer needs (Kaye, 2014). In the current system, low wages and lack of training resources has led to high LTSS staff turnover, limiting access to services and resulting in poor continuity of care (Kaye, 2014). Since MLTSS also encourages the move from institutional services to community-based services, agencies will need to build their capacity to provide additional supports to individuals and families during these transitions. Given the existing work force concerns, it is uncertain how the MLTSS programs will be able to adequately support both existing service recipients and any new service recipients transitioning to more community-based care. If individuals with IDD experience decreases in access to services in MLTSS, then this may result in more reliance on family caregivers.

Another concern is the MCO's potential lack of knowledge and expertise about the complex needs of adults with IDD and the LTSS system (President's Committee for People with Intellectual Disabilities, 2012). If MCOs lack understanding of adults with IDD, then they may not provide an adequate scope of health and wellness services necessary to address the needs and health disparities of adults with IDD. They may be unfamiliar with person-centered planning as well as family-centered planning, which could result in less individualization of supports and services to meet the needs of the adult with IDD and support their family.

New relationships formed between MCOs and LTSS providers will require capacity building for both entities and potentially more enhanced state oversight (Kaye, 2014). There is a high degree of diversity in LTSS providers ranging from large credentialed agencies to small

privately owned providers (Burwell & Kasten, 2013). Managed care organizations are accustomed to working with larger health services providers, but not with small privately owned providers. The lack of familiarity by the MCOs with small providers and the small providers' lack of knowledge about MCOs may lead to difficulty in contract negotiations between the MCOs and these smaller agencies. The small providers will also have to spend time enhancing their ability to prepare accurate pricing for their services and will also need to learn new billing practices under MLTSS. There are concerns that states will lack the capacity to properly oversee the successful transition to MLTSS ensuring accurate rate setting and the inclusion of a broad range of LTSS providers in the MCO network resulting in less consumer access and choice (President's Committee for People with Intellectual Disabilities, 2012).

In addition, there are uncertainties about the application of the medical model of providing health services to non-medical LTSS (President's Committee for People with Intellectual Disabilities, 2012). Treating LTSS like a more predictable set of medical services needed to treat a health condition might mean that individuals are not allowed true choice of services and supports, detracting from individualization of services and supports. Adults with IDD already experience difficulty accessing needed services and supports due to low staff wages resulting in vacancies and staff turnover (Larson, Hewitt, & Lakin, 2004). It may prove challenging for MCOs to put together a broad network of providers with expertise in IDD resulting in less consumer access, less consumer choice, and less individualization of supports and services. If MLTSS results in more difficulty in accessing needed services and supports, then it could detract from reducing health disparities for adults with IDD (President's Committee for People with Intellectual Disabilities, 2012).

Finally, there are concerns about MLTSS enrollment. If MLTSS enrollment is mandatory for individuals with IDD, then their choice is limited to selecting the MCO with which they will enroll (National Council on Disability, 2013). Once enrolled in the MCO, the individual with IDD will only be able to select among approved providers within the MCO network. If the MCO is unable to provide access to a broad selection of LTSS providers, then consumer access and choice will be limited. States have flexibility to decide if enrollment in MLTSS will be mandatory or voluntary for individuals with IDD. Disability advocacy groups recommend voluntary enrollment for MLTSS to ensure that the individual with IDD can advocate for their desired method for receiving services and supports (National Council on Disability, 2013).

Best Practices for MLTSS

In response to concerns, uncertainty, and the growing trend for states to provide MLTSS for individuals with IDD, advocacy groups, administrative agencies, and other experts in evaluation of Medicaid services are recommending best practices for designing and implementing MLTSS programs. These best practice recommendations for managed care are specific to MLTSS for individuals with IDD and include guidance on the planning, implementation, and evaluation of MLTSS. Recently, there have been indications that these best practices will move beyond recommendations and become regulatory guidelines for managed care implementation. The Centers for Medicare and Medicaid Services (2015) released a new proposed rule covering MLTSS. The CMS Proposed Rule was released May 26, 2015 and is currently out for public review and comment.

In planning for MLTSS, careful consideration should be taken to ensure that the range of supports and services provided are both integrated and comprehensive. Integration of LTSS, behavioral health services and health care services is best practice, even if they are financed

through different mechanisms (Consortium for Citizens with Disabilities, 2012; Dembner, 2012; National Council on Disability, 2013). Enrollees need to have access to both a LTSS care coordinator and a health-services care coordinator or at least a care coordinator with expertise across fields (National Council on Disability, 2013). Managed care organizations need to offer a comprehensive range of LTSS that include access to durable medical equipment and assistive technology to promote community living (Consortium for Citizens with Disabilities, 2012; Dembner, 2012; National Council on Disability, 2013). A critical service for individuals with IDD is supported employment, as community-based employment is an important pathway to community inclusion (Consortium for Citizens with Disabilities, 2012; National Council on Disability, 2013).

The MCO's provider network needs to be large and diverse in order to meet the needs of enrollees on an individualized basis (Centers for Medicare and Medicaid Services, 2013a; Consortium for Citizens with Disabilities, 2012; Dembner, 2012). A strong provider network will ensure participants having choice in selecting their provider and will allow for continuity of care for individuals wanting to remain with their providers utilized prior to the MLTSS transition (Centers for Medicare and Medicaid Services, 2013a; Consortium for Citizens with Disabilities, 2012; National Council on Disability, 2013). Managed care will not be successful unless the MCO can develop an adequate provider network inclusive of the needs of adults with IDD (Kastner, Walsh, & Criscione, 1997).

Given the reliance on family caregivers, MLTSS programs need to be responsive to the needs of both the individual with IDD and their family caregiver(s) so the caregiver(s) can continue to support and advocate for the individual with IDD (Dembner, 2012; National Council on Disability, 2013). Family support services help families make informed choices about

supports and services by building upon existing family strengths and resources, making it more likely that the individual with IDD will continue to be involved in the community and avoid less community-inclusive institutional care (Heller & Schindler, 2009; University of Minnesota, 2006). Types of family support services include respite (services provided so family caregiver can take a break from the care giving role), family education, family counseling, cash assistance, information and referral, and parent support groups (Braddock & Hemp, 2008). The Consortium for Citizens with Disabilities (2012) additionally recommends payment to family members as support providers in MLTSS. Consumer choice means that individuals may choose a provider who is a friend or a family member and MCOs need to be prepared with financial intermediary options available to consumers who choose non-agency based providers (Kaye, 2014).

Truven Health Analytics (2013) proposes specific timeline tasks in the development of a MLTSS program from planning, implementation, and evaluation. Specific tasks in the first (planning) phase involve engaging stakeholders, developing a communications plan, sharing program goals, consulting with CMS, assessing operational capacity, and creating a work plan. In order to implement MLTSS, a state must obtain legislative and CMS approval. Once approval is received, the implementation of MLTSS involves phasing in operational resources, selecting contractors and third party vendors, educating and informing providers, completing readiness reviews, and enrollment. Finally, once the program is operational, early experiences in the new MLTSS system need to be reviewed and the MLTSS system needs to be continually monitored in order to make corrections (Truven Health Analytics, 2013).

Planning for the transition to MLTSS is a critical component. States proposing a move to MLTSS need to plan for long implementation timelines in order to allow for consultation with stakeholders including individuals with IDD, families, providers, and advocacy groups (Centers

for Medicare and Medicaid Services, 2013a; Summer, 2011). These long planning timelines will help the state create a smooth transition process (Centers for Medicare and Medicaid Services, 2013a). Providers with expertise in IDD need to be involved in the design of MLTSS (National Council on Disability, 2013). A readiness assessment is recommended to evaluate the state's capacity and the MCO's capacity to handle diverse populations (National Council on Disability, 2013). After the readiness assessment is completed and the state has determined the MLTSS transition is feasible, then the implementation should take place in a phase-in approach rather than all at once (National Council on Disability, 2013). At the state level, it is recommended that MLTSS policies should include a requirement for states to develop a strategic plan with long-term goals for implementing MLTSS (National Council on Disability, 2013).

Stakeholder engagement is a pivotal aspect of MLTSS programs and should occur throughout planning, implementation, and evaluation (Truven Health Analytics, 2013). A formal process needs to be in place for ongoing stakeholder engagement and education both prior to and after implementation (Centers for Medicare and Medicaid Services, 2013a). In Wisconsin, one-quarter of the board of directors of each MCO is made up of individuals with disabilities (or other enrollee types) or a family caregiver and Arizona requires all MCOs to have a consumer advisory board (Dembner, 2012). It is also valuable to engage providers with expertise in services and supports for individuals with IDD during program design and implementation (National Council on Disability, 2013).

Community living, avoiding discrimination, and consumer choice are values that should be reflected in MLTSS. Services and supports provided need to comply with the Americans with Disabilities Act, Rehabilitation Act and the Olmstead v. L.C. decision supporting community living and inclusion (Centers for Medicare and Medicaid Services, 2013a; Consortium for

Citizens with Disabilities, 2012; National Council on Disability, 2013). Community living over institutional care is a core goal of MLTSS and MLTSS should encourage these transitions (Centers for Medicare and Medicaid Services, 2013a; National Council on Disability, 2013). The transition to MLTSS is not just about improving health and wellness, but also about promoting inclusion and independence of individuals with IDD (National Council on Disability, 2013).

In order to avoid discriminatory practices, compliance with civil rights means that services and supports need to be cognitively and physically accessible for the individual with IDD so they are assured choice and availability of community supports (Consortium for Citizens with Disabilities, 2012; National Council on Disability, 2013). Communications and education strategies that are accessible ensure that individuals with IDD are fully informed of their rights, their options, and their obligations (Centers for Medicare and Medicaid Services, 2013a; National Council on Disability, 2013).

Services need to be provided in a person-centered approach to allow for consumer choice (Consortium for Citizens with Disabilities, 2012). Person-centered means the individual with IDD decides on their goals and manages their services and supports (Consortium for Citizens with Disabilities, 2012). Individuals with IDD need to be allowed a choice of providers to ensure person-centeredness, even those outside the MCO network as long as the provider follows the MCO payment structure (Centers for Medicare and Medicaid Services, 2013a; National Council on Disability, 2013).

Specific recommendations about participant enrollment and rights to file grievances provide important protections for individuals with IDD. Even though MCOs may be allowed to require mandatory enrollment, best practice recommendations are to utilize voluntary enrollment until the state can demonstrate they are able to meet the diverse needs of all potential participants

(Consortium for Citizens with Disabilities, 2012; Dembner, 2012). States would prefer mandatory enrollment to decrease administrative burden, whereas advocates would prefer voluntary enrollment to maintain consumer choice (Kaye, 2014). Even if the state uses voluntary enrollment, there should still be a provision allowing individuals the freedom to opt-out of MLTSS if their needs are not being met (Consortium for Citizens with Disabilities, 2012). If states make enrollment into MLTSS mandatory, then consumers must be assured choice between a minimum of two plans (Dembner, 2012). Once people are seeking services, states' policies should promote a single point-of- entry for MLTSS enrollment (Kaye, 2014). Clear procedures need to be in place for consumer oversight and protection including the ability to file a grievance and access to a fair hearing with continuation of services during an appeal (Consortium for Citizens with Disabilities, 2012; Dembner, 2012; National Council on Disability, 2013). State administrators need to be prepared for potential problems with enrollment and have a plan in place for swift response prior to implementing MLTSS (Truven Health Analytics, 2013).

There are also best practices recommendations regarding the payment structure and operations of MCOs. Capitation rates should be based on total payments for services and supports over multiple years (Consortium for Citizens with Disabilities, 2012). There should not be disincentives in place for the enrollment of individuals with high level of need (Consortium for Citizens with Disabilities, 2012). The payment structure needs to align with community-based care as a priority and allow flexibility for consumer choice (Centers for Medicare and Medicaid Services, 2013a; National Council on Disability, 2013). Any cost savings achieved by MLTSS should be used to address unmet needs of current and potential MLTSS recipients (National Council on Disability, 2013). According to 2010 statistics, there are 303,909 individuals with IDD on waiting lists to receive HCBS (Kaiser, 2014). Federal policies in

MLTSS should require states to include plans to reinvest MLTSS savings into expanding service availability to reduce and eliminate wait lists for LTSS (President's Committee for People with Intellectual Disabilities, 2012).

Finally, regarding evaluation, it is considered best practice to have clear state oversight of MCO operations and to have quality management processes in place. The state needs to provide oversight on the evaluation and operations of MCOs, including their payment structure (Centers for Medicare and Medicaid Services, 2013a; National Council on Disability, 2013). States need to invest in information technology infrastructure to allow for more efficient oversight of the managed care system (National Council on Disability, 2013). There is currently a lack of good MLTSS quality measures and states using MLTSS can provide their data to assist with the development of a MLTSS quality measure (Summer, 2011). The government needs to promote more efforts to evaluate MLTSS, and states and MCOs need to have a quality measurement system in place to continually monitor quality and performance (National Council on Disability, 2013). The quality management system needs to identify the program's effectiveness in helping individuals meet their goals and, at a minimum, monitor the MLTSS system's person-centeredness, stakeholder responsiveness, and qualified personnel availability (National Council on Disability, 2013).

States need to ensure policies about MLTSS quality management that are not just about health, but also about quality of life outcomes (Consortium for Citizens with Disabilities, 2012; National Council on Disability, 2013; President's Committee for People with Intellectual Disabilities, 2012). State requirements for quality reporting should include qualitative data from consumers and not just administrative data on enrollment and expenditures (Kaye, 2014). There is no current recommended uniform assessment for MLTSS. A review of a MLTSS assessments

strategies from five states reveals that at a minimum a uniform assessment should include activities of daily living, instrumental activities of daily living, information on caregivers and natural supports, cognition, health status, and behavioral health status (Ingram, Lind, & Ensslin, 2013).

Potential Benefits from MLTSS

With best practice considerations in mind, there are benefits that can be realized from moving to MLTSS. One critical benefit of moving to MLTSS is the ability to meet previously unmet needs of adults with IDD (President's Committee for People with Intellectual Disabilities, 2012). Meeting unmet needs can be accomplished through using cost savings to reduce the number of people on waiting lists for services (Dembner, 2012; President's Committee for People with Intellectual Disabilities, 2012). In addition, it is hoped that MLTSS can lead to more funding resources with higher provider rates to ensure a capable and steady LTSS workforce improving continuity of care (Kaye, 2014).

Cost savings from MLTSS can also be used to expand service offerings to adults with IDD (National Council on Disability, 2013). These new services can include prevention and wellness services designed to address issues contributing to health disparities (President's Committee for People with Intellectual Disabilities, 2012). The expansion of service offerings can result in more self-advocate choice, or self-determination, in decisions regarding the type and variety of supports and services.

In addition, states utilizing MLTSS must require MCOs to complete a person-centered planning process in which the individual with IDD identifies their services and supports based on their goals (Centers for Medicare and Medicaid Services, 2013a). The Centers for Medicare and Medicaid Services (2014) recently updated their HCBS rules to ensure person-centered planning,

which will further support requirements for MCOs to offer truly person-centered planning.

Expansion of service offerings combined with a focus on person-centered planning could result in more self-determination and an individualization of services and supports.

It is estimated that only one in ten family caregivers received support services, therefore the potential exists to add new services designed to meet the unmet needs of family caregivers (Braddock et al., 2013). A best practice recommendation is to require MLTSS programs to be responsive to both the needs of adults with IDD and family caregivers (Dembner, 2012; National Council on Disability, 2013). Opportunities exist within the move to managed care arrangements to expand family support service options and to also pay family caregivers for support provided (Consortium for Citizens with Disabilities, (2012).

Another potential benefit of MLTSS would be to improve care coordination (President's Committee for People with Intellectual Disabilities, 2012). In MLTSS, MCOs can coordinate needed services and supports across health care, behavioral health care, and LTSS (National Council on Disability, 2013). This improved care coordination holds promise to help individuals with IDD better prevent and manage secondary health and mental health conditions, reducing health disparities and improving wellness. There is difficulty in identifying mental health disorders amongst individuals with IDD due to behaviors being attributed to their diagnosis or difficulty with communication (Krahn et al., 2006). Coordination across health care, behavioral health and LTSS can enhance identification and treatment of mental health concerns among people with IDD.

The integration of physical health and behavioral health is a high priority under MLTSS (Connolly & Paradise, 2012). Integrating health, behavioral health, and LTSS into one coordinating agency can improve care coordination while also reducing administrative overhead

(Kastner et al., 1997). This integration of services and supports will mean contracts between agencies need to include data sharing across entities in order to promote health and wellness and decrease the need for inpatient services (Connolly & Paradise, 2012). Care coordination is no longer solely about medical services under MLTSS, therefore care coordinators will need to be trained about coordinating physical health, behavioral health, and LTSS (Highsmith & Somers, 2003). There are opportunities for cross-training between professionals to increase their skill set to work effectively as partners with adults with IDD and their family caregivers.

Another goal of MLTSS is to move more people into community-based care instead of institutional care (President's Committee for People with Intellectual Disabilities, 2012). A focus on community inclusion within implementation of MLTSS can contribute to reducing environmental and social barriers experienced by adults with IDD in existing health and behavioral health systems (National Council on Disability, 2013). There are opportunities for self-advocates and family caregivers to be involved in the training and oversight of MCOs to ensure they are providing adequate services and supports reflective of the needs of the IDD population and encouraging inclusion in the community (President's Committee for People with Intellectual Disabilities, 2012; Saucier et al., 2012).

The move to MLTSS can also build capacity in public health and behavioral health research. The Administration for Community Living (ACL) and the National Institute on Disability and Rehabilitation Research recently funded the Community Living Policy Center at the University of California San Francisco (Kaye, 2014). The new investment in community living research is a sign of potential future research funding possibilities regarding MLTSS. The National Council on Disability (2013) recommends that the Department of Health and Human Services should invest more research funding to evaluate best practices in MLTSS.

The concept of MLTSS in its very nature calls for increased collaboration in policy. At the federal policy level, CMS can work with the ACL on their oversight of MLTSS reviewing state proposals given the expertise in disability and community living that exists in the ACL (National Council on Disability, 2013; President's Committee for People with Intellectual Disabilities, 2012). The ACL merges the efforts of the Administration on Aging, the Administration on Intellectual and Developmental Disabilities, and the Health and Human Services Office of Disability (Kaye, 2014). Therefore, ACL's staff has expertise across several disciplines served under MLTSS making them an ideal collaborator with CMS (Kaye, 2014). The existing HCBS waiver system is very fragmented by populations served and MLTSS provides an opportunity to decrease the fragmentation by merging services and supports for diverse groups under one service system (Kaye, 2014). There is an opportunity for the Department of Education to collaborate with the Department of Health and Human Services on best practices to assist young adults transitioning from school-based services to adult services and supports received under MLTSS (President's Committee for People with Intellectual Disabilities, 2012).

The move towards MLTSS offers opportunities for capacity building in policy. At the federal level, it is acknowledged that CMS needs to work to expand their workforce to be able to adequately monitor and evaluate MLTSS (National Council on Disability, 2013; President's Committee for People with Intellectual Disabilities, 2012). The ACL can also work to fund training and technical assistance services to individuals with IDD and their family caregivers under MLTSS (President's Committee for People with Intellectual Disabilities, 2012).

In summary, the move to MLTSS for adults with IDD is a complicated and uncertain venture. At this time, the evidence regarding the MLTSS is mixed as to whether or not MLTSS

can improve care coordination and access to services while also reducing costs. There are proposed benefits of MLTSS to be realized, but also a great deal of concerns about MLTSS. Uncertainty regarding MLTSS for adults with IDD has resulted in the development of suggested best practice recommendations and new proposed CMS regulations. There is a need for more research regarding the implementation of MLTSS for adults with IDD to explore these best practice recommendations.

APPENDIX B: INTERVIEW PROTOCOLS

State/Regional Agency Director Interview Protocol

Introduction

Hello, my name is Heather Williamson and I am a doctoral candidate in public health at the University of South Florida completing my dissertation. Thank you so much for volunteering your time today to complete this interview.

The goal of my dissertation is to describe the KanCare implementation process for adults with intellectual and/or developmental disabilities and their family caregivers. The study will provide an overall summary with lessons learned from the KanCare implementation.

The purpose of this interview is to gather your thoughts and opinions about the implementation of KanCare. Your responses will inform the study, which may be shared with other states to help inform their managed care efforts.

All of your responses are confidential. This means that your interview responses will only be shared with the research team members. We will ensure that any information we include in our report does not identify you as a respondent. Information in final reports will combine information from all of the participants and any quotes used will not be identifiable. None of the research team has any association with KanCare.

Remember, you do not have to talk about anything you do not want to. You can also end the interview at any time.

I am interested in all of your experiences, ideas, comments, and suggestions. There are no right or wrong answers. This interview should take between 45 minutes to an hour to complete. With your permission, I would also like to tape-record the interview so I do not miss any of your comments. Are you okay with being tape-recorded? I know how busy you are and I really appreciate the time you are spending with me today.

Do you have any questions before we begin?

1) Describe for me your role in KanCare.

Probes: How long have you been in this role? What prior experience did you have working with individuals with intellectual and/or developmental disabilities? [Opening]
[Opening]

2) Think back to when KanCare for adults with intellectual and/or developmental disabilities was being implemented statewide (February 2014). During this transition, what was the experience like? [describe initial impressions]

3) How would you describe the main goals of KanCare for the IDD population? [expectations, rationale behind]

4) Describe for me the experience of implementing KanCare long-term services and supports for the IDD population. [implementation lessons learned]

Probes: What has worked well? What has not worked well? Has your role changed?

5) How would you describe your relationships with the managed care organizations? [state oversight]

Probes: What has worked well? What has not worked well?

6) How is KanCare ensuring consumer choice for adults with IDD? [IDD values]

Probe: Can you give me an example?

7) How is KanCare promoting community inclusion for adults with IDD? [IDD values]

Probe: Can you give me an example?

8) What do you see as benefits of KanCare for adults with IDD? [goals, IDD values of community inclusion and consumer choice discussed here]

Probes: Which of these is most important?

9) Describe for me how KanCare supports family caregivers? [family caregiver role]

Probes: What has worked well? What has not worked well?

10) How has KanCare included family caregivers of adults with IDD in the implementation? [family caregiver role]

Probes: What has worked well? What has not worked well? What would you do differently?

11) Help me understand more details about the assessment process. Are family caregivers asked about any of the following? You can just indicate please yes or no:

Alternative residential living options

Balancing their wishes with those of their loved one

Additional caregiving responsibilities

Additional family members involved in support

Additional resources for support

Planning for the future

Their physical health
Their mental health
Their stress level
Their life satisfaction
Satisfaction with services

12) Imagine if you could go back and implement KanCare for adults with IDD again, what would you keep the same? What could have gone better? [implementation lessons learned]

13) If you had to meet with a colleague in another state transitioning to managed care for the IDD population, what are the top three things you would tell them? [take home message]

Probes: Assessment? Care coordination? Including family caregivers?

14) Is there anything else about KanCare for adults with IDD that you would like to share?

Thank you again for your time today.

State/Regional Level Representative Interview Protocol

Introduction

Hello, my name is Heather Williamson and I am a doctoral candidate in public health at the University of South Florida completing my dissertation. Thank you so much for volunteering your time today to complete this interview.

The goal of my dissertation is to describe the KanCare implementation process for adults with intellectual and/or developmental disabilities and their family caregivers. The study will provide an overall summary with lessons learned from the KanCare implementation.

The purpose of this interview is to gather your thoughts and opinions about the implementation of KanCare. Your responses will inform the study, which may be shared with other states to help inform their managed care efforts.

All of your responses are confidential. This means that your interview responses will only be shared with the research team members. We will ensure that any information we include in our report does not identify you as a respondent. Information in final reports will combine information from all of the participants and any quotes used will not be identifiable. None of the research team has any association with KanCare.

Remember, you do not have to talk about anything you do not want to. You can also end the interview at any time.

I am interested in all of your experiences, ideas, comments, and suggestions. There are no right or wrong answers. This interview should take between 45 minutes to an hour to complete. With your permission, I would also like to tape-record the interview so I do not miss any of your comments. Are you okay with being tape-recorded? I know how busy you are and I really appreciate the time you are spending with me today.

Do you have any questions before we begin?

- 1) Describe for me your role in the intellectual and/or developmental disability community.
Probes: How long have you been in this role? What prior experience did you have working with individuals with intellectual and developmental disabilities? [Opening]
 [Opening]
- 2) Think back to when KanCare for adults with intellectual and/or developmental disabilities was being implemented statewide (February 2014). During this transition, what was the experience like? [describe initial impressions]
- 3) How would you describe the main goals of KanCare for the IDD population? [expectations, rationale behind]
Probe: What did you expect to see change with the move to KanCare for the IDD population? [expectations, rationale behind]
- 4) How would you describe the implementation of KanCare long-term services and supports for the IDD population? [implementation lessons learned]
Probes: What has worked well? What has not worked well?
- 5) How would you describe your relationships with the managed care organizations? [stakeholder input]
Probes: What has worked well? What has not worked well?
- 6) What do you see as benefits of KanCare for adults with IDD? [goals, IDD values of community inclusion and consumer choice discussed here]
Probes: Which of these is most important?
- 7) How is KanCare ensuring consumer choice for adults with IDD? [IDD values]
Probe: Can you give me an example?
- 8) How is KanCare promoting community inclusion for adults with IDD? [IDD values]
Probe: Can you give me an example?
- 9) Describe for me how KanCare supports family caregivers? [family caregiver role]
Probes: What has worked well? What has not worked well?
- 10) How has KanCare included family caregivers of adults with IDD in the implementation? [family caregiver role]
Probes: What has worked well? What has not worked well? What would you do differently?
- 11) Help me understand more details about the assessment process. Are family caregivers asked about any of the following? You can just indicate please yes or no:
 Alternative residential living options
 Balancing their wishes with those of their loved one
 Additional caregiving responsibilities
 Additional family members involved in support

Additional resources for support
Planning for the future
Their physical health
Their mental health
Their stress level
Their life satisfaction
Satisfaction with services

12) Imagine if you could go back and implement KanCare for adults with IDD again, what would you keep the same? What could have gone better? [implementation lessons learned]

13) If you had to meet with a colleague in another state transitioning to managed care for the IDD population, what are the top three things you would tell them? [take home message]
Probes: Assessment? Care coordination? Including family caregivers?

14) Is there anything else about KanCare for adults with IDD that you would like to share?

Thank you again for your time today.

State – MCO Representative Interview Protocol

Introduction

Hello, my name is Heather Williamson and I am a doctoral candidate in public health at the University of South Florida completing my dissertation. Thank you so much for volunteering your time today to complete this interview.

The goal of my dissertation is to describe the KanCare implementation process for adults with intellectual and/or developmental disabilities and their family caregivers. The study will provide an overall summary with lessons learned from the KanCare implementation.

The purpose of this interview is to gather your thoughts and opinions about the implementation of KanCare. Your responses will inform the study, which may be shared with other states to help inform their managed care efforts.

All of your responses are confidential. This means that your interview responses will only be shared with the research team members. We will ensure that any information we include in our report does not identify you as a respondent. Information in final reports will combine information from all of the participants and any quotes used will not be identifiable. None of the research team has any association with KanCare.

Remember, you do not have to talk about anything you do not want to. You can also end the interview at any time.

I am interested in all of your experiences, ideas, comments, and suggestions. There are no right or wrong answers. This interview should take between 45 minutes to an hour to complete. With your permission, I would also like to tape-record the interview so I do not miss any of your comments. Are you okay with being tape-recorded? I know how busy you are and I really appreciate the time you are spending with me today.

Do you have any questions before we begin?

1) Describe for me your role in KanCare.

Probes: How long have you been in this role? What prior experience did you have working with individuals with intellectual and/or developmental disabilities? [Opening]

2) Think back to when KanCare for adults with intellectual and/or developmental disabilities was being implemented statewide (February 2014). During this transition, what was the experience like? [describe initial impressions]

3) How would you describe the main goals of KanCare for the IDD population? [expectations, rationale behind]

4) Describe for me the experience of implementing KanCare long-term services and supports for the IDD population. [implementation lessons learned]

Probes: What has worked well? What has not worked well?

5) How would you describe your relationship with the state agencies? [state oversight]

Probes: What has worked well? What has not worked well?

6) How is KanCare ensuring consumer choice for adults with IDD? [IDD values]

Probe: Can you give me an example?

7) How is KanCare promoting community inclusion for adults with IDD? [IDD values]

Probe: Can you give me an example?

8) What do you see as benefits of KanCare for adults with IDD? [goals, IDD values of community inclusion and consumer choice discussed here]

Probes: Which of these is most important?

9) Describe for me how KanCare supports family caregivers? [family caregiver role]

Probes: What has worked well? What has not worked well?

10) How has KanCare included family caregivers of adults with IDD in the implementation? [family caregiver role]

Probes: What has worked well? What has not worked well? What would you do differently?

11) Help me understand more details about the assessment process. Are family caregivers asked about any of the following? You can just indicate please yes or no:

Alternative residential living options

Balancing their wishes with those of their loved one

Additional caregiving responsibilities

Additional family members involved in support

Additional resources for support

Planning for the future

Their physical health

Their mental health

Their stress level
Their life satisfaction
Satisfaction with services

12) Imagine if you could go back and implement KanCare for adults with IDD again, what would you keep the same? What could have gone better? [implementation lessons learned]

13) If you had to meet with a colleague in another state transitioning to managed care for the IDD population, what are the top three things you would tell them? [take home message]
Probes: Assessment? Care coordination? Including family caregivers?

14) Is there anything else about KanCare for adults with IDD that you would like to share?

Thank you again for your time today.

Provider Interview Protocol

Introduction

Hello, my name is Heather Williamson and I am a doctoral candidate in public health at the University of South Florida completing my dissertation. Thank you so much for volunteering your time today to complete this interview.

The goal of my dissertation is to describe the KanCare implementation process for adults with intellectual and/or developmental disabilities and their family caregivers. The study will provide an overall summary with lessons learned from the KanCare implementation.

The purpose of this interview is to gather your thoughts and opinions about the implementation of KanCare. Your responses will inform the study which may be shared with other states to help inform their managed care efforts.

All of your responses are confidential. This means that your interview responses will only be shared with the research team members. We will ensure that any information we include in our report does not identify you as a respondent. Information in final reports will combine information from all of the participants and any quotes used will not be identifiable. None of the research team has any association with KanCare.

Remember, you do not have to talk about anything you do not want to. You can also end the interview at any time.

I am interested in all of your experiences, ideas, comments, and suggestions. There are no right or wrong answers. This interview should take between 45 minutes to an hour to complete. With your permission, I would also like to tape-record the interview so I do not miss any of your comments. Are you okay with being tape-recorded? I know how busy you are and I really appreciate the time you are spending with me today.

Do you have any questions before we begin?

- 1) Describe for me your role in KanCare for adults with intellectual and/or developmental disabilities. Probe: How long have you been in this role? [Opening]
- 2) Think back to when KanCare for adults with intellectual and/or developmental disabilities was being implemented statewide (February 2014). During this transition, what was the experience like? [describe initial impressions]
- 3) What did you expect to see change with the move to KanCare for the IDD population? [expectations, rationale behind]
- 4) How would you describe the implementation of KanCare long-term services and supports for the IDD population? [implementation lessons learned]
Probes: What has worked well? What has not worked well?
- 5) How would you describe the working relationship between the managed care organization (Amerigroup, Sunflower, United) and the Community Developmental Disabilities Organizations?
Probes: What has worked well? What has not worked well?
- 6) What do you see as benefits of KanCare for adults with IDD? [goals, care coordination, access to care]
Probes: Access to care changes? Care coordination changes? Which of these is most important?
- 7) Describe for me the experience of transitioning families into KanCare for long-term services and supports?
Probes: What has worked well? What has not worked well? Or
What would you keep the same? What would you change? Or
Role of targeted case manager? Role of MCO care coordinator?
- 8) Describe for me how KanCare supports family caregivers? [family caregiver role]
Probes: What has worked well? What has not worked well?
- 9) How has KanCare included family caregivers of adults with IDD? [family caregiver role]
Probes: What has worked well? What has not worked well? What would you do differently?
- 10) Help me understand more details about the assessment process. Are family caregivers asked about any of the following? You can just indicate please yes or no:
 - Alternative residential living options
 - Balancing their wishes with those of their loved one
 - Additional caregiving responsibilities
 - Additional family members involved in support
 - Additional resources for support
 - Planning for the future
 - Their physical health
 - Their mental health

Their stress level
Their life satisfaction
Satisfaction with services

11) If you had to meet with a colleague in another state transitioning to managed care for the IDD population, what are the top three things you would tell them? [take home message]
Probes: Assessment? Care coordination? Including family caregivers?

12) Is there anything else about KanCare for adults with IDD that you would like to share?

Thank you again for your time today.

Family Caregiver Interview Protocol

Introduction

Hello, my name is Heather Williamson and I am a doctoral candidate in public health at the University of South Florida completing my dissertation. Thank you so much for volunteering your time today to complete this interview.

The goal of my dissertation is to describe the KanCare implementation process for adults with intellectual and/or developmental disabilities and their family caregivers. The study will provide an overall summary with lessons learned from the KanCare implementation.

The purpose of this interview is to gather your thoughts and opinions about the implementation of KanCare. Your responses will inform the study which may be shared with other states to help inform their managed care efforts.

All of your responses are confidential. This means that your interview responses will only be shared with the research team members. We will ensure that any information we include in our report does not identify you as a respondent. Information in final reports will combine information from all of the participants and any quotes used will not be identifiable. None of the research team has any association with KanCare.

Remember, you do not have to talk about anything you do not want to. You can also end the interview at any time.

I am interested in all of your experiences, ideas, comments, and suggestions. There are no right or wrong answers. This interview should take between 45 minutes to an hour to complete. With your permission, I would also like to tape-record the interview so I do not miss any of your comments. Are you okay with being tape-recorded? I know how busy you are and I really appreciate the time you are spending with me today.

Do you have any questions before we begin?

- 1) Tell me about your relationship with your son/daughter/sibling with an intellectual and/or developmental disability. Probe: How are you involved in decisions about their services and supports? [Opening]
- 2) Think back to when KanCare for adults with intellectual and/or developmental disabilities was being implemented statewide (February 2014). During this transition, what was the experience like? [describe initial impressions]
- 3) What did you expect to see change with the move to KanCare? [expectations, rationale behind]
- 4) Describe for me the experience of transitioning into KanCare for waiver services?
[implementation lessons learned]
Probes: What worked well? What did not work well?
- 5) How would you describe the experience of receiving waiver services through KanCare?
Probes: What has worked well? What has not worked well?
- 6) What do you see as benefits of KanCare?
Probes: Access to care changes? Care coordination changes? Which of these is most important?
- 7) As a family caregiver, what are ways that you feel supported by KanCare? [family caregiver role]
Probes: What supports are helpful? What supports are not helpful? What materials have been provided to you that were helpful? Can you provide me an example?
- 8) As a family caregiver, how have you been included in decisions under KanCare? [family caregiver role]
Probes: How would you want to be included?
- 9) Help me understand more details about the assessment process. Have you been asked about any of the following items? You can just indicate yes or no:
 - Alternative residential living options
 - Balancing your wishes with those of your loved one
 - Additional caregiving responsibilities
 - Additional family members involved in support
 - Additional resources for support
 - Planning for the future
 - Your physical health
 - Your mental health
 - Your stress level
 - Your life satisfaction
 - Satisfaction with services
- 10) If you had a friend moving to Kansas from another state who needed to access IDD waiver services, what would you tell him or her? [take home message]

11) Suppose you were in charge of KanCare and could change anything, what would you do to change the program?

12) Is there anything else about your experience with KanCare that you would like to share?

Thank you again for your time today.

If you know another family caregiver that you think might be interested in speaking with me, please feel free to share my contact information with them.

APPENDIX C: CODEBOOK

Study Purpose: The study’s overall purpose is to describe the current implementation of MLTSS for adults with IDD and their family caregivers in Kansas.

The study’s specific aims are:

Aim 1. To understand the rationale behind and what is actually happening with MLTSS for adults with IDD in Kansas;

Aim 2: To understand how service coordination providers and family caregivers perceive care coordination and access to services for adults with IDD in MLTSS;

Aim 3: To understand how family caregivers and their roles are recognized in MLTSS for adults with IDD.

Codebook Updates: Version 1 are Piori Codes are based on best practice recommendations from CMS, NCD, and CCD; Version 2 updated based on reviewing journal and notes; Version 3 updated after coding 3 transcripts and organized to be in alphabetical order as seen in NVivo; Version 4 updated after coding provider transcripts and identifying new codes under care coordination (Care Coordinator Role, TCM Communication with MCOs) and access to services (TCM services); Version 5 updated after coding first three family caregiver transcripts to add the code Families as Employers; Version 6 updated during final analysis by moving person-centered as a theme and instead put the codes in that them consumer selects provider and ensure consumer choice under consumer education theme, removed code for “foster care” as this was only one situation and referred to support for a child

| Main Category/Theme (Parent Node) | Code (Child Nodes) | Definition |
|-----------------------------------|---|--|
| Access to services | Behavior management | Addressing behavior concerns proactively |
| | Communications with MCO and family regarding services | General concerns with difficulty in communicating with MCO to get answers to questions |
| | Crisis management | Enrolling individuals in waiver services previously not served who are in a crisis situation which requires immediate access to services |
| | Dental Care | Ability to access needed dental services, challenges faced here |
| | Durable medical equipment | Ability to access needed DMEs, challenges faced here |
| | Health Care | Ability to access needed health services, primary care physician, challenges faced here |
| | Incentive for accessing preventative care or completing preventative health behaviors | Providing incentives for people with IDD to seek out preventative care or completing preventative health behaviors |
| | Initial evaluation | Describe the initial evaluation process of all members |
| | LTSS | Ability to access LTSS (provided under waiver), challenges faced here |
| | Medication management | Addressing medication management to improve |

| Main Category/Theme (Parent Node) | Code (Child Nodes) | Definition |
|------------------------------------|---|--|
| | | health or mental health |
| | Mental Health | Ability to access needed mental health services, challenges faced here |
| | Preventative care | Ability to access needed preventative care services, challenges faced here |
| | Rural vs. urban | Experiences with accessing services different if rural instead of urban |
| | Targeted case management | Access to targeted case management services and time/effort |
| | Value added services | New services provided by MCOs that were not previously covered by Medicaid |
| Care coordination | | |
| Care coordination | Care coordination process | The process of coordinating care needs (health care, LTSS, behavioral health, dental) of individual with IDD |
| | Care Coordinator caseload | The caseload of individuals carried by each Care Coordinator from the MCO |
| | Care Coordinator communication with TCM | Communications between MCO Care Coordinator and Targeted Case Manager |
| | Care Coordinator communication with family | Communications between MCO Care Coordinator and families |
| | Care Coordinator role | Describes the role of Care Coordinator |
| | Care Coordinator knowledge-experience | The knowledge and experience level of Care Coordinators regarding the needs of people with IDD |
| | Care Coordinator turnover | Describes issues related to Care Coordinator staffing turnover |
| | TCM communication with MCO | Communications between TCMs and the MCOs (general company not the Care Coordinator) |
| CMS/Federal Oversight | | |
| CMS/Federal Oversight | Contract requirements | Guidelines from CMS on contracts |
| | Underserved wait list addressed | Individuals on underserved wait list were provided services |
| Community inclusion | | |
| Community inclusion | Avoid institutional care | Encourage services to be provided in a home and community based setting |
| | Employment | Supporting employment in community settings |
| Consumer education/choice (| | |
| Consumer education/choice (| Consumer education activities | Efforts made by state/MCO to education the public about KanCare |
| | Informed decision making | Having an understanding as to why you have chosen to select an MCO |
| | Reasons MCOs were selected | Families describe their reasoning for selecting an MCO |
| | Consumer selects providers | Consumers are allowed to select their own choice of providers |
| | Ensure consumer choice in planning process (person-centered plan) | The wishes of the individual with IDD are honored in the development of their annual individualized service plan |

| Main Category/Theme (Parent Node) | Code (Child Nodes) | Definition |
|--|--|---|
| Engagement with stakeholders (families, self-advocates, providers) (| Including stakeholders in implementation | Stakeholder feedback is considered in implementation |
| | Including stakeholders in planning | Stakeholder feedback is considered in planning |
| | Not including stakeholders in implementation | Stakeholder feedback is not considered in implementation |
| | Not including stakeholders in planning | Stakeholder feedback is not considered in planning |
| Family caregiver role acknowledgement | Acknowledge family caregiver role and needs (family-centered plan) | The needs of the family caregiver are identified and addressed in the development of the annual individualized service plan |
| | Advocacy support | Having support from a provider to help advocate for needed services |
| | Families as employers | Families describe having to manage their employees (support staff) and the payroll, hours, etc. |
| | Family relationships with MCOs | Describe family caregivers relationships with MCOs |
| | Paid family caregivers | Describe experiences of family caregivers being paid to provide care |
| | Respite | Paid supports to provide the family caregiver a break |
| Goals of managed care | Goals of managed care | Goals for moving into a managed care model |
| Grievance and appeal | Clear grievance process | People understand how to file a grievance or appeal |
| | Ombudsman | Description of how Ombudsman is doing in addressing grievances |
| | Unclear grievance process | People don't understand how to file a grievance or appeal |
| Lessons learned | Advice to other families | Advice provided to other families in a state moving into managed care |
| | Advice to other providers | Advice provided to other providers in a state moving into managed care |
| | Advice to other states | Advice provided to other states moving into managed care |
| MCO Structure (policies) | IDD specific policies/procedures | Examples of policies/procedures specific to IDD community |
| | MCO investments | Examples of investments the MCOs are making to benefit people with IDD |
| | MCO knowledge/experience | Describes perceptions of MCO's knowledge |

| Main Category/Theme (Parent Node) | Code (Child Nodes) | Definition |
|-----------------------------------|--|--|
| | | and/or experience with LTSS and IDD |
| | MCO request for proposal process | Suggestions for request for proposals for MCOs |
| Planning | | |
| Planning | Adequate time | Including time ahead of implementation to plan for structure and process. |
| | Lack of planning | Not including enough time to plan or inadequate planning |
| | Pilot | Testing the system before it goes fully live |
| Provider network | | |
| | Access to new providers | Bringing new providers into the system |
| | Loss of providers | The loss of providers in the system since implementation |
| | Maintain existing providers | Maintaining existing providers in the MCO provider network |
| | Provider contracts | Establishing contracts with providers to include in the network |
| | Provider payments | Payment to providers for their services |
| | Relationship between MCO and providers | Describe relationship between MCOs and providers |
| Reinvest cost savings | | |
| | Existing wait list | Discussions about the existing wait list for services. |
| | Lack of cost savings | MCOs not experienced cost savings yet |
| State oversight | | |
| | State requirements | State requirements to guide implementation |
| Transition experience | | |
| | Emotions | Describe emotions felt during the transition process |
| | Experience | Describe overall experience of the implementation |
| | Fears | Describe fears regarding managed care |
| | Lack of transparency | Difficulty in knowing how system is working due to lack of transparency in the system. |
| | Making system more complex | Describes KanCare as adding extra layer and making more complex system |
| | More consistency in funding | Move to KanCare brought more consistency in funding decisions across the state |
| | Resistance | Describe resistance to change experienced |
| | Shift of control | Descriptions regarding managed care feeling like a shift from local control to state control |

APPENDIX D: IRB APPROVAL LETTER



RESEARCH INTEGRITY AND COMPLIANCE
Institutional Review Boards, FWA No. 00001669
12901 Bruce B. Downs Blvd., MDC035 • Tampa, FL 33612-4799
(813) 974-5638 • FAX (813) 974-7091

December 16, 2014

Heather Williamson, M.B.A.
Community and Family Health
13201 Bruce B. Downs Blvd. MDC 56
Tampa, FL 33612

RE: Expedited Approval for Initial Review

IRB#: Pro00019671

Title: Implementation of Medicaid Managed Long-Term Services and Supports for Adults with Intellectual and Developmental Disabilities: A State's Experience

Study Approval Period: 12/16/2014 to 12/16/2015

Dear Ms. Williamson:

On 12/16/2014, the Institutional Review Board (IRB) reviewed and **APPROVED** the above application and all documents outlined below.

Approved Item(s):

Protocol Document(s):

[IRB Protocol.Version5.12.12.14.docx](#)

Consent/Assent Document(s)*:

[IRB Verbal Consent Form.v1](#) **granted a waiver of documentation

*Please use only the official IRB stamped informed consent/assent document(s) found under the "Attachments" tab. Please note, these consent/assent document(s) are only valid during the approval period indicated at the top of the form(s). **Waivers are not stamped.

It was the determination of the IRB that your study qualified for expedited review which includes activities that (1) present no more than minimal risk to human subjects, and (2) involve only procedures listed in one or more of the categories outlined below. The IRB may review research through the expedited review procedure authorized by 45CFR46.110 and 21 CFR 56.110. The research proposed in this study is categorized under the following expedited review

category:

(6) Collection of data from voice, video, digital, or image recordings made for research purposes.

(7) Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.

Your study qualifies for a waiver of the requirements for the documentation of informed consent as outlined in the federal regulations at 45CFR46.117(c) which states that an IRB may waive the requirement for the investigator to obtain a signed consent form for some or all subjects if it finds either: (1) That the only record linking the subject and the research would be the consent document and the principal risk would be potential harm resulting from a breach of confidentiality. Each subject will be asked whether the subject wants documentation linking the subject with the research, and the subject's wishes will govern; or (2) That the research presents no more than minimal risk of harm to subjects and involves no procedures for which written consent is normally required outside of the research context.

As the principal investigator of this study, it is your responsibility to conduct this study in accordance with IRB policies and procedures and as approved by the IRB. Any changes to the approved research must be submitted to the IRB for review and approval by an amendment.

We appreciate your dedication to the ethical conduct of human subject research at the University of South Florida and your continued commitment to human research protections. If you have any questions regarding this matter, please call 813-974-5638.

Sincerely,



John Schinka, Ph.D., Chairperson
USF Institutional Review Board

APPENDIX E: PERMISSION TO USE UNIFIED FQOL FIGURES

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Introduction

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