

SERVICE DISRUPTED:

Managed Long-Term Services and Supports
Falling Short for Adults with Intellectual and
Developmental Disabilities



Because we all should have a say
in decisions that affect **our health**



TABLE OF CONTENTS

INTRODUCTION	3
WHAT IS LTSS?.....	4
WHAT ARE INTELLECTUAL AND DEVELOPMENTAL DISABILITIES?.....	4
MANAGED CARE AND IDD SERVICES	5
KEY ISSUES	7
- <i>Services Disrupted, Denied or Out of Reach</i>	7
- <i>Limited Consumer Engagement in Planning, Implementation and Oversight</i>	9
- <i>Weak Oversight and Protections</i>	10
GLIMMERS OF HOPE	11
SPOTLIGHT ON HEALTH EQUITY	13
RECOMMENDATIONS	13
MOVING FORWARD.....	16
APPENDIX A: MLTSS PROGRAM CHART	17
APPENDIX B: SELECTED RESOURCES.....	17
ENDNOTES.....	18

AUTHORS

Madison Tallant, *Program and Policy
Coordinator, Center for Consumer
Engagement in Health Innovation*

Alice Dembner, *Senior Policy Analyst, Long-
Term Services and Supports; Program Director,
Substance Use Disorders and Justice-Involved
Populations*

ACKNOWLEDGEMENTS

The authors would like to thank Quynh Chi
Nguyen for her assistance with this project.
We also are grateful to all of the advocates
and consumers who took time to share their
stories with us, and to the other stakeholders
who shared their expertise.

November 2019

INTRODUCTION

Faced with the rapid advance of managed care in Medicaid, many advocates across the country are fighting to maintain the intellectual and developmental disability (IDD) service systems that they worked so hard to build. The existing fee-for-service (FFS) system provides many consumers extensive home and community based long-term services and supports (LTSS), although the range of services and ease of access varies state to state. Improvements are needed to ensure adults get the services they want and that are essential to living well in their communities. Commercial (for-profit) managed care offers states the siren-song combination of service improvement, better coordination of LTSS with other health care and program savings. However, there are other means of achieving integration, quality care and value for public spending that may work better for this population than managed care.

The eight states evaluated in this paper are using different models of managed LTSS for adults, with results ranging from somewhat beneficial to terrible. In no state have consumers resoundingly gained better access to the full range of high-quality, coordinated services they need.

The models used range from for-profit companies managing LTSS integrated with all other Medicaid services, to government managed LTSS only, to a mix of public and nonprofit regional plans that cover LTSS and some other health care. In the for-profit models, the plans are fully financially responsible for providing services for a fixed fee. In the other models, the plans' financial responsibility ranges from full-risk to shared-risk with the state.

In several of the states with nonprofit or public managed care, long-existing wait lists for home and community based services (HCBS) were eliminated or greatly reduced, and consumers gained access to employment and services such as respite care and community living supports. However, turnover of providers and care managers, extreme variation of service availability from county to county, and other problems are common.

In Kansas and Iowa, the rollout of commercial managed care for LTSS plus physical and behavioral health was disastrous for IDD consumers and their families. These two states hastily shifted services for all populations from FFS to managed care simultaneously. During the rocky transition and implementation, consumers suffered hardship and injury from service cuts and severed longstanding relationships with trusted providers. Care coordination failed, leaving families navigating new systems almost entirely on their own.

Individuals with IDD require stability, and the chaos caused by managed care in these states left an indelible mark. Across the country IDD consumers now approach managed care with strong fact-based skepticism and fear, even in states where managed care has been around for decades and is not run by for-profit companies.

Several states are reconsidering their approaches to IDD LTSS system improvements and whether managed care via commercial plans is an appropriate model. For example, Texas has delayed the transition of IDD services to managed care from 2021 to 2027¹. Arizona and Wisconsin also dropped plans for commercial managed LTSS when faced with strong consumer opposition. In this moment of rethinking, there is a prime opportunity for advocates to jump in and steer these conversations in a positive direction, whether that is barring a transition to managed long-term services and supports (MLTSS) for this population or fighting to make MLTSS systems better.

In this paper, Community Catalyst presents findings from an assessment of how IDD consumers are faring in MLTSS, and recommends strategies for ensuring consumers are better served.

WHAT IS LTSS?

Long-term services and supports (LTSS), also called long-term care, includes everything from institutional care to home and community based supports such as help with chores, personal care, transportation, supervision and cueing, skills development, and maintaining and gaining employment. These services are essential to help Medicaid beneficiaries, especially seniors and people with disabilities, live with dignity and as much independence and community participation as possible. For people with complex illnesses or disabilities, robust LTSS focused on personal needs and preferences can spell the difference between merely surviving and thriving.

In previous work, we have advised that states proceed with caution in adopting managed care for LTSS as no state has offered a model of success in all aspects of an MLTSS program. Extra precaution should be taken when transitioning LTSS services for individuals with IDD to a managed care environment. This population's unique needs make managed care even more complex and potentially harmful. Managed care has become the predominant delivery system for Medicaid in most states². The number of MLTSS programs and enrollment has more than doubled since 2012. As of 2018, 24 states operated an MLTSS program³. MLTSS programs for IDD services have also been growing in number. Currently, eight states (Arizona, Arkansas, Iowa, Kansas, Michigan, North Carolina, Tennessee, Wisconsin) have implemented statewide Medicaid managed care for IDD HCBS services, and another three have taken clear steps toward MLTSS for people with IDD (Nebraska, New York, Texas).⁴ As more states consider moving IDD LTSS into managed care, it is important to take stock of how well existing MLTSS IDD programs are serving consumers.

WHAT ARE INTELLECTUAL AND DEVELOPMENTAL DISABILITIES?

Developmental disabilities are chronic disabilities that can be cognitive and/or physical. Intellectual disabilities are a type of developmental disability that affects intellectual functioning (reasoning, learning, problem solving) and adaptive behaviors (a range of social and practical skills). Intellectual and developmental disabilities often co-occur⁵.

Individuals with IDD often need more and different supports than other populations who require LTSS services (such as older adults and people with physical disabilities). Services typically will be required over an individual's entire lifetime, and their needs can vary greatly over time and from person to person, even if they carry a similar diagnosis. In addition, many people need support for employment, self-determination and behavioral issues that are different from the needs of other LTSS populations. Finally, building a robust provider network is challenging because of the breadth and depth of specialized services needed. Failure to consider the unique needs of this population and the challenge they pose for managed care will result in ineffectual or harmful programs.

Below are some examples of the unique needs of the IDD population that states should bear in mind as they consider transitioning to MLTSS for this population:

Employment Supports

Many individuals with IDD want to be employed in community settings and earn competitive wages. To achieve this, individuals with IDD may need assistance developing workplace interpersonal skills in addition to career exploration support and on-the-job training⁶. Needed supports may vary from week to week, and employers may also need training to ensure they can provide a welcoming and inclusive environment for workers with IDD.

Employment supports and policies must be tailored to work with the network of public programs that many individuals with IDD rely on to meet their needs and with the income and asset limits associated with those programs. Some individuals may be hesitant to begin working for fear of losing their eligibility for Medicaid.

Self-Determination

Many individuals with IDD have historically been kept from exercising their right to self-determination, which is the ability to decide what parts of their life they want to control. Lack of support, segregation and denial of dignity-of-risk⁷ have all served as barriers to self-determination⁸. Supports for self-determination for adults with IDD could include teaching skills such as choice-making and problem solving as well as providing opportunities to strengthen self-advocacy (the ability to identify and promote one's wants and needs)⁹. The needs and desires of the individual receiving services must be central to the care-planning process. Facilitating self-determination is critical if this to occur.

Provider Network

Services for IDD have grown organically from the community. Many providers are small community-based organizations that have little or no experience contracting with managed care companies. Family members provide extensive uncompensated care. In addition, families and individuals have built strong relationships with providers over many years, resulting in deep trust and extensive knowledge of an individual's needs and situation.

MANAGED CARE AND IDD SERVICES

Most Medicaid LTSS for people with IDD is currently provided through waivers that offer a broad range of home and community based services provided fee-for-service. All waiver programs include some level of case management, and services are high touch. Many individuals with IDD and their families know the state officials overseeing the programs and have close relationships with their case managers and providers.

[National Core Indicators](#) data from 2017-2018 suggests that consumers are generally satisfied with the care they receive. This NCI data tallies results from states that use FFS as well as managed care structures, but the bulk of the data is from FFS. As of 2016, only seven percent of Medicaid LTSS for people with IDD were paid for using managed care¹⁰. Therefore, we assume that the data largely represents the experience of individuals in FFS systems. Ninety-one percent of respondents to NCI's In-Person Survey (administered directly to individuals with IDD who receive at least one service in addition to case management) reported that they feel the supports they receive help them live a good life. The NCI survey also shows there is room for improvement. Only 63 percent of In Person Survey respondents chose their staff, only 18 percent of respondents had a job in the community¹¹, 25 percent said they would like to live somewhere else, and 19 percent report that there is at least one place (home, day program, work, etc.) where they feel afraid or scared¹².

Managed care for people with IDD offers the opportunity to increase integration of care across physical health, mental health and substance use disorders and LTSS if the program is structured to include all of these areas or require coordination across siloed programs. Managed care can also improve service range and quality if the state structures payment and oversight to get more value for the public funds expended. Opportunities include expanding the use of self-direction, increasing health and wellness programs and addressing growing waiting lists¹³. However, there are significant risks for consumers if states or managed care organizations (MCOs) use managed care to cut services, squeeze out community providers or medicalize support services¹⁴.

Creating consumer-focused managed care programs for this population is difficult. The most significant challenge for commercial managed care aimed at achieving profits or states seeking to cut Medicaid costs is that there are few cost-savings to be had without cutting services. This derives from the fact that much of LTSS for people with IDD has shifted from institutional care to HCBS (although there is still progress to be made in this area in a few states), and Medicaid rates for IDD services are already fairly low¹⁵. Additionally, IDD provider networks are not well-acquainted with managed care, many commercial MCOs are not familiar with how small community-based providers operate¹⁶ or with IDD services, and existing workforce shortages create gaps in many MCO provider networks.

In our assessment, we focused on eight states – Arizona, Arkansas, Iowa, Kansas, Michigan, North Carolina, Tennessee and Wisconsin – that have statewide Medicaid managed care programs for individuals with IDD.

These eight states are taking a variety of approaches to MLTSS. In some of the programs we assessed, LTSS services were integrated with physical and behavioral health, while in others they were managed separately. Some states are using commercial MCOs while others are using provider-led organizations, regional nonprofit entities, or public agencies. A few states are transitioning existing care management structures for LTSS services to new forms of managed care while others are implementing MLTSS for the first time.

Three states with existing MLTSS programs (Arizona, Michigan and North Carolina) are either considering or actively implementing structural changes to their programs. Arizona, which previously managed all IDD services through the state Division of Developmental Disabilities, is now moving medical and behavioral health services to commercial MCOs but keeping LTSS services with the state. Michigan, which uses public managing entities called prepaid inpatient health plans (PIHPs), is evaluating alternative financing models through a new pilot program. In North Carolina, the existing nonprofit, quasi-governmental managing entities are responsible for LTSS, mental health and substance use services for people with DD and/or behavioral health conditions, but the state is planning to move all health and LTSS services into integrated managed care in the next few years, delivered by commercial and nonprofit plans.

“When I first got started trying to make inroads with the ECF Choices, I didn’t speak the language. I didn’t know the bureaucracy. I didn’t know the channels of hierarchy, of who to talk to, and when things went bad who to move up to, or how to move anything an inch...This system is not designed for parents. It is designed for bureaucrats.”

*- Dana Tucker
Parent, Tennessee*

Our assessment included:

- Interviews with consumers, state-based advocacy organizations, national advocacy organizations, providers, health plans and subject matter experts
- A review of state waivers, program documents and MCO contracts
- A review of publicly available consumer grievance and complaint data

Overall, we found the move to managed care has been particularly problematic for individuals with intellectual and developmental disabilities and on the whole, consumers in MLTSS programs are seeing few benefits. Kansas and Iowa present the grimmest reality of what can happen when a state rushes into large systems change without adequate preparation and with a main goal of saving money. Other states have managed, or are managing, the transition more carefully, resulting in some promising practices. Tennessee, Wisconsin and Michigan, while not perfect, have been successful at using the move to managed care in a creative way to address some long-standing needs in the IDD community.

Consumers and advocates across the eight states focused on three problems:

- Services disrupted, denied or out of reach;
- Limited stakeholder engagement;
- Poor program oversight.

KEY ISSUES

Services Disrupted, Denied or Out of Reach

Disruption in Provider Relationships

Small, independent community-based organizations and individuals are the primary providers of services for people with IDD. In Iowa, Kansas and Arkansas stakeholders talked about losing providers of all types, including direct care workers, during the transition to managed care. While provider shortages across the LTSS industry make provider losses problematic for every community, losses among IDD providers are particularly devastating because many consumers and families have long-standing relationships with their providers and case managers, built on deep understanding of the unique needs of those individuals.

In MLTSS programs for people with IDD, these losses were the result of flawed transitions to the new managed care model or issues with payments. Stakeholders in these same states also said consumers were confused about which of their providers were in managed care networks and how to ensure they did not lose their long-time caregivers.

In all states, providers had to learn how to negotiate and contract with MCOs as well as navigate new billing and administrative systems. Rates do not account for the increased administrative time providers spend on these new practices, so provider resources are stretched increasingly thin. Delayed payments forced some providers to close or leave MCO networks entirely. In Arkansas, a company that provides services to individuals with IDD sued the state over delayed and missing payments.¹⁷ The case was dismissed, but there are plans to refile.

“In the original system, we had the same case manager for eleven years. Now, two and a half years into managed care, we’re on our fifth case manager. The turnover makes it hard to educate each individual on the needs of my son. It’s hard to help my son understand who he can and cannot trust. There just isn’t enough time to help him distinguish who this new person is and why they are there before they are gone again.”

*- Lisa Heddens
Parent, Iowa*

Network Inadequacy

As providers leave MCO networks, or refuse to enter networks from the start, consumers have fewer options to meet their needs. Consumers across states said they had problems finding direct service workers, behavioral health providers and case managers who were trained in the unique needs of people with IDD. For families in rural areas, these shortages are even greater.

The shortage of direct service workers is a national crisis that did not begin with managed care. There is insufficient data on the number of direct service providers who have experience working with individuals with IDD. Factors contributing to the shortage include low wages, challenging workload, greater demand for services and competition for direct service workers from home care agencies that serve people with physical disabilities and older

people. Some states are requiring MCOs, and/or partnering with them, to try to build provider capacity. Consumer advocates say this is an essential, but long-term strategy.

Problems with Case Management

Stakeholders in Iowa and Kansas report multiple changes to case management since entering managed care. Some consumers experienced constant turnover in case managers or a noticeable reduction in quality. This relationship is paramount for families and consumers with IDD. Case managers not only help develop service plans, but work alongside families as they navigate the IDD service system. For many families, their relationship with the case manager was the most longstanding they had within the service system. One stakeholder described the case manager relationship like the relationship someone would have with a very responsive and well-connected primary care doctor. It is the foundation on which the rest of an individual's care can be built. These relationships may take longer to rebuild for individuals whose disability includes cognitive limitations and because of the time needed for case managers to distinguish the individual's needs and goals from those of their family or other caregivers. In Kansas, advocates also report that some MCO case managers are not informing individuals and families of the full range of services available, nor of their rights to appeal service denials.

"The MCOs came in saying that they were going to save everyone money, but it doesn't look like any money has actually been saved. They have taken services away from people and cut hours though."

*- Marilyn Kubler
Parent, Kansas*

Service Cuts and Denials

Iowa has been the most dramatic example of service cuts in the wake of a transition to MLTSS. In 2017, Disability Rights Iowa filed a lawsuit in response to systematic service cuts lowans with disabilities experienced after the state moved to managed care¹⁸. In Kansas, consumers experienced both service cuts and long waits for services. Consumers and consumer advocates strongly fear that other states transitioning to managed care with a goal of saving money or achieving a quick fix will experience similar outcomes.

In Michigan, which ended its waiting list for services, all eligible consumers receive some services. However, they have inequitable access to true person-centered supports.

Some managed care agencies provide individuals access to a wide range of supports that enable them to live independently in the community, while other agencies offer little choice of housing and few services supporting self-determination, according to stakeholders. The state has enacted some limited incentives to try to even out access, but this has done little to solve the problem.

In Their Own Words

Delaine Petersen, of Iowa, Speaking About Her Children Matthew and Leslie

"I have two children with the same disability, profound intellectual disability. My daughter, Leslie, is still living. My son, Matthew, passed away several years ago. Before managed care, we had continuity, our case manager was able to develop a service plan that really fit Leslie's needs.

In what seemed like the dead of the night in 2015, the state started talking about how they were going to transition to this new system that was going to save a whole lot of money. They were going to hand off this care to people who were bidding for the business. There was no consumer participation in these discussions. There was no rationale given on why this was going to be a better system.

The first 18 months were scary, but we had the same case manager to help us navigate the change. Amerihealth seemed to be a partner with us when we built our service plan, but then they left Iowa because they were losing so much money. We were assigned to United Healthcare. At this point, Leslie absolutely needed a new wheelchair. She has to have a specialty made cushion, so it's not a standard chair. They refused to pay for it.

Then United announced they were leaving the state, and now we are being transitioned to Iowa Total Care, our third MCO. We recently had an annual planning meeting and were able to lay out the kinds of services that we want. Thankfully we have a case manager who "gets it," but I don't know if we will get everything approved.

Leslie is one of 144 people who are on a waitlist at a local provider – who served her for over 30 years – for an appropriate level of worker because she has complex needs. Unfortunately, they cannot get adequate reimbursement to be competitive for workers. We've moved some of her hours to a consumer choice option to give us more flexibility. Since then we've been able to find a few people who work in the school system to pick this up as a second job. It's hard though because our economy is pretty good right now and people can work at McDonald's for more than they can make providing these services. Leslie is fortunate because I'm retired and I can work on this all day. I don't know how people who are working do it, how they can take care of their loved ones in this system."



Delaine and Duane Petersen with their children, Matthew and Leslie.

Limited Consumer Engagement in Planning, Implementation and Oversight

In nearly every state, consumer advocates identified significant limitations in state efforts to engage them:

- Meetings were too far away or held at times that consumers and family members could not attend.
- Public meetings meant that the audience contained providers or plan representatives, which prevented some consumers and families from feeling comfortable enough to speak up.

- Information sessions were too short, moved too quickly, and used too much jargon.
- Public meetings were not adequately tailored to the needs of consumers with IDD, and states and MCOs did not provide the [supports](#) needed for these consumers to participate.
- In Kansas, advocates said events felt “staged” and not intended to secure meaningful feedback from attendees.
- In Tennessee, the state discontinued meetings for months after consumers packed a meeting to raise concerns about the program.
- In Michigan, recent announcement of system reform came very unexpectedly. Extensive consumer engagement followed the announcement via a workgroup, but advocates say the legislature has ignored the recommendations put forward.

The lack of meaningful, robust engagement with consumers and families has caused confusion and fear as well as programs that are not well-suited for individuals with IDD. In states where managed care is still in the planning stages, or where it has only recently been implemented, families and many consumers are extremely anxious about the changes managed care will bring for the services they rely on to maintain health and independence.

“There were a lot of problems with how it rolled out. I used to joke and say that it ‘rolled out with three flat tires.’”

*- Leisa Hammett
Parent and Regional Organizer,
Tennessee*

In Michigan, the state mandates that the managing entities, called Prepaid Inpatient Health Plans (PIHPs), include consumers in the development of the PIHP funding applications. However, there is little enforcement, and consumer engagement varies greatly from PIHP to PIHP, advocates said.

Stakeholders in Iowa, Kansas and Arkansas said the transition to managed care happened too fast. Several advocates said the state’s deadlines to move to managed care did not leave enough time for comprehensive stakeholder engagement, integration of feedback into planning or an adequate transition period for providers, consumers and family members to the new model. Arkansas delayed implementation phases due to issues with the rollout of the managed care program. Multiple changes to the program’s timeline or implementation schedule can magnify confusion for consumers.

Despite challenges with engagement to date, advocates expressed great desire to work with state officials and MCOs to rectify issues in MLTSS programs.

Weak Oversight and Protections

Many stakeholders expressed concern about the lack of program oversight in their states. Several individuals said states relinquished too many oversight responsibilities to the managed care entities and cut state program staff. Strong oversight practices that enforce compliance with managed care contracts and regulations are the cornerstone of any effective managed care program. In Michigan, there is strong language in both PIHP contracts and state policy about person-centered services and self-direction, but stakeholders said the state does not provide much oversight. In North Carolina, the [State Auditor](#) faulted the state Department of Health and Human Services this year for weak oversight of managed care plans.

Stakeholders in all states referenced ways that consumers could protect themselves from service reductions and resolve disputes with MCOs, but this was frequently limited to appeals to the MCO or reports to the ombudsmen. Several advocates said that many consumers were unaware of the options available to them to address an issue; others said consumers are often scared to report issues for fear of retaliation.

“The state didn’t want to be involved in the day-to-day administration, and cut [staff]. There aren’t the horses to pull the wagon. The previous administrations didn’t leave enough people to perform oversight or enforce provisions unless it’s financial or egregious.”

*- Dohn Hoyle
The Arc Michigan*

We attempted an examination of publicly available consumer grievance and appeals data to understand common issues individuals with IDD encounter in MLTSS programs. To find this information we looked for reports from ombudsman programs, state health departments, and in some instances the MCOs themselves. In [Iowa](#), [Kansas](#) and [Wisconsin](#), we found some grievance and complaint data, but not specific to individuals with IDD, or not in a form that could be compared to other LTSS populations.

Without the combination of strong contract management plus an independent ombudsman, or other independent oversight body, it is incredibly difficult to quickly identify and rectify system-wide issues. Overall, advocates and consumers work to address poor service on the back end, rather than rely on states and regulatory bodies to proactively monitor and prevent poor outcomes. Consumers

may have to wait months for their issue to be rectified, service to be reinstated or service plans to be adjusted. In the LTSS world, delays could mean a greater chance of institutionalization, family economic hardship or injury.

Compounding the lack of oversight is the paucity of meaningful consumer-driven quality measures specific to HCBS IDD services, and tailored for use in managed care. This gap exists for all HCBS across all populations. Some states are using the effective [National Core Indicators](#) tool in FFS HCBS, but either not using it for managed LTSS or not disaggregating results for managed care versus FFS. Disaggregation would require increasing the sample size in each state to maintain validity. This is a missed opportunity to gather data on how consumers are faring, and how managed LTSS is affecting their quality of life.

GLIMMERS OF HOPE

In some states, managed care has benefitted some consumers. In Tennessee, even though there are still issues with the program, Employment and Community First (ECF) Choices is helping adolescents and young adults who had previously been unable to receive services. Many families now have access to personal assistance hours, respite and home modification. The program has also increased employment of individuals with IDD in integrated settings. According to a quarterly report filed with CMS, the number of adults with IDD employed in an integrated setting and earning at least minimum wage increased by 20% from 1,097 to 1,312 in the first year of ECF Choices. Additionally, more than 500 people with a developmental disability other than an intellectual disability were able to receive HCBS services through TennCare for the first time¹⁹.

In Wisconsin, some MCOs have had success using value-based payments (also called outcome-based reimbursement) to incentivize competitive integrated employment. One MCO, Inklusia, Inc., saw a 70 percent increase in the number of people employed in competitive integrated employment in the six years following implementation of value-based payment²⁰. Advocates report there is still room for improvement in employment support.

Through managed care, Michigan successfully ended its waiting list for IDD services²¹, achieving one of advocates’ biggest hopes for the program. Those eligible to receive services are getting them, advocates said. Despite the variability in services across the state, advocates have not heard complaints of individuals not receiving any services. Arizona also does not have a waitlist, but advocates report there are still some individuals who are not receiving services because they cannot find a provider.



In Their Own Words

Melanie Lutenbacher, of Tennessee, Speaking About Her Son Jacob

My son Jacob, who has both an intellectual and a physical disability, just turned thirty years old. When he is doing well, he's fairly high-functioning, but he does have trouble making decisions and determining who is and is not safe to be with. He is an Eagle

Scout and has been a part of the same troop since he was a little guy. He is very social, loves sports and music, and participates in a Metro Parks Adult Program, Special Olympics and the Best Buddies program.

Before ECF Choices he had intermittent services. We were forever meeting new staff because of the constant turnover, and it all seemed to be more trouble than it was worth sometimes. We structured all of his programs on our own and tried very hard to keep him busy and active. Over time, we were able to build a pretty good bubble around Jacob and keep him involved in the community.

Jacob was still living at home when we started with ECF Choices. We went through the exploration and discovery phases [of person-centered planning] and had an endless circle of "meet and greets" with providers, some of whom we never heard from again. The people who showed up to our house were young, inexperienced and fairly clueless about what was available and what kinds of supports would benefit Jacob. ECF seems very staff dependent, not program dependent yet, so success often depends on the individual provider.

Eventually we had a young lady come to work with Jacob who was just great. She was a great communicator, could think outside the box and worked with Jacob to use his experiences from helping in the Boy Scout Camp Trading Post to secure his current part-time job as cashier in a grocery store. He loves it. He knows all of his shoppers and really enjoys getting to interact with people at work. After that, his ECF coordinator asked if he was interested in living on his own. Jacob wasn't really into that at first, but he started to get interested in the idea and eventually made the transition to live in an apartment. It was hard at first, but he loves it now. He lives with two other guys. They are close in age, have a lot of common interests and have become really good friends.

ECF hasn't been without its challenges though. We thought that the providers would be able to go in and help Jacob continue to develop independent living skills, like budgeting, meal planning, cooking and cleaning, but that hasn't really happened. We've had a revolving door of staff and a lot of them don't seem prepared for the kind of support that Jacob needs. It takes a lot more skill to help someone learn how to do things on their own rather than just doing things for them. The turnover in staff has meant things often fall through the cracks. The multiple transitions are stressful for Jacob. Communication breaks down and it takes a while for him to gain traction again. Nutrition has also been a huge issue. Jacob's triglycerides have been out of whack since he moved into the apartment, and he has put on weight. I want the staff to work with Jacob to learn how to plan and make nutritious meals so he minimizes his risk for diabetes or a heart attack.

We thought being part of this program would lessen the amount of time we would need to contribute to his everyday needs, but in many ways, it has actually increased the amount of time we spend overseeing Jacob's care. Despite these bumps, ECF Choices has been an awesome opportunity for Jacob.

ECF Choices continues to be an exciting journey for our family, but for me, at times it has been a little like building the plane while in the air. For Jacob, he likes feeling more independent. Things are still a little scary at times but he takes a lot of pride in living on his own and being buddies with his roommates. It's *his* house and *his* home, and I think that is really important. Everyone should have that feeling.

SPOTLIGHT ON HEALTH EQUITY

We found limited information about how MLTSS programs serve individuals with IDD based on race, geographic location and gender identity. There is some research that suggests individuals with IDD have disparate health outcomes from their non-disabled peers and little information about what disparities exist within the IDD community. People with IDD are at elevated risk for a number of health conditions including: obesity, psychiatric disorders, sensory impairment, high cholesterol, hypertension and cardiovascular disease. People with IDD who have been hospitalized have higher rates of complications than their non-disabled peers. Some research suggests that black women with IDD are less likely to receive breast cancer screenings than white women with IDD²². In addition, advocates in several states identified language access issues, immigration status and geographic location as potential barriers to care for some individuals in the IDD community.

RECOMMENDATIONS

Given the problematic rollout of MLTSS for people with IDD, we recommend the following. We have included state examples where possible, but we have not found promising practices for every recommendation.

Resist Any Plan to Move IDD LTSS Services into Managed Care Solely to Save Money, and Proceed with Extreme Caution in Other Cases

Consumer experiences in Iowa and Kansas highlight the potential harm to consumers if states move to managed care for the primary objective of saving money. Cost savings are likely unattainable, and a singular focus on savings may incentivize service cuts. State policymakers should center objectives to improve outcomes and care quality. Advocates should resist plans that ignore program outcomes in favor of focusing on cost.

States that propose managed care with consumer-focused goals must proceed with caution as the unique needs of this population make managed care even more complex and potentially harmful. Advocates should be vigilant and press for detailed justification of any proposed move to managed care, especially any plans to implement commercial managed care, for this population.

Authentically Engage Consumers in Program Planning, Implementation and Oversight

State policymakers must consult consumers to achieve effective programs. Consumers are the experts in what they need and often have practical knowledge and suggestions about how to accomplish that. Authentic engagement, by nature, takes significant time and resources but will result in better outcomes. Advocates should press for robust engagement and resist any plan that does not involve meaningful consumer participation. While no state is perfect, the following examples show how states can more meaningfully engage consumers in all states of planning, implementation and oversight.

Extensive Consultation

- The ECF Choices program in **Tennessee** began with extensive communication between the state and consumers over a two-year planning period (see slide 13 of this presentation from the TN Division of Health Care Finance & Administration). During this process, the state brought multiple concept papers and program proposals to the consumer community for feedback, which was then integrated into future iterations of program documents. This iterative process allowed consumers to provide meaningful input into the program's creation, ensuring that it more closely aligned with the needs of the community.

Sharing Documents in Accessible Formats

- **Tennessee** also released a concept paper for its managed LTSS program written specifically for individuals with I/DD. This paper was developed with assistance from the state's Council on Developmental Disabilities. Including DD councils, consumers and consumer advocates in the development of materials for consumers will make program communication and engagement more effective. This discussion has continued through ECF Choices implementation and advocates have continued to push for program improvements.

Make Meetings More Accessible

- States could enhance engagement during implementation by improving supports for consumer participation in community and consumer engagement meetings. The National Association of State Directors of Developmental Disabilities Services (NASDDDS) has a [handbook](#) on making sure meetings and presentations are more inclusive and accommodating for individuals with IDD.

Provide Consumers and Advocates Many Seats at the Table

- Consumers and advocates make up one third of **North Carolina's** Behavioral Health/IDD Tailored Plan Subcommittee (see slides 25 and 26 of this [presentation](#)), which is helping to shape a new managed care system. The subcommittee reviews and provides feedback on many aspects of the Tailored Plans' design including eligibility and enrollment, network adequacy and roll-out schedule.

Build a Robust Provider Network, Including Experienced Case Managers and Direct Service Workers

State policymakers should take steps to raise provider rates, ensure adequate training and preparation for new billing systems, and build timelines that prevent provider losses and service disruption. In doing this, states must ensure that increased rates reach the direct services providers. Advocates should push for implementation timelines and policies that specifically enhance the direct service workforce.

Several states have promising practices to retain providers and enhance the direct service workforce.

Increase Direct Care Workforce Wages

- In 2017, the **Wisconsin** legislature approved \$60.8 million to increase the direct care portion of MLTSS capitation rates. The legislature authorized this funding to help pay for raises, bonuses, or additional paid time off as well as any increases in provider payroll taxes that result from increasing wages. The first payments were distributed in June 2018 and the last payment is set for December 2019²³. The Wisconsin Department of Health Services will compile survey data on how the funds were used and how effective the payments were at meeting the state's direct care workforce needs²⁴.

Require MCOs to Build the Workforce Pipeline

- **Tennessee's** statewide MCO contract requires MCOs to "actively participate with TennCare, other TennCare managed care contractors, and other stakeholders as part of a statewide initiative to develop and implement strategies to increase the pool of qualified direct support staff and to improve retention of qualified direct support staff." These activities could include partnering with colleges or technical schools, developing training and certification programs for direct support staff or providing incentives to providers who employ specially trained/certified staff. MCOs are also required to collaborate with the Department of Intellectual and Developmental Disabilities on training opportunities for personal care providers (see [contract](#) page 274-275). This could serve as model contract language for other states looking to involve MCOs in workforce development initiatives for IDD direct service or personal care providers.

Exercise Strong Oversight

States need to maintain robust and experienced staff to oversee managed care programs. They must exercise strong contract management, and solicit, monitor and act on consumer feedback. Advocates should push for strong oversight practices that allow system-wide issues to be quickly identified and rectified.

Several states offer examples of oversight mechanisms that include consumer voices, but they only serve as a starting point. We recommend states establish statewide oversight boards, comprised of a majority of consumers and consumer advocates.

Establish an Independent Ombudsman

- **Wisconsin's** [ombudsman program](#), run by Disability Rights Wisconsin, is for individuals aged 18-59 who are eligible for Family Care or the self-directed services program IRIS (Include, Respect, I Self-Direct). Locating ombudsman programs in agencies that consumers already trust may increase the likelihood that consumers use these services to report or address issues with their care.

Survey Consumers about How the Program is Working

- In **Tennessee**, the state is considering expanding the [People Talking to People Project](#), a quality improvement project housed at The Arc Tennessee, to the ECF Choices program. This project employs individuals with disabilities to conduct consumer-satisfaction interviews to monitor the quality of the state's IDD Waiver services. This survey has four questions that automatically trigger further investigation by the state if a negative response is given. The questions are:
 - Do staff treat you well and with respect?
 - Are things that are important to you included in your service plan?
 - Do you have enough privacy?
 - Do you know how to report a complaint?

We recommend states include questions that ask consumers about the outcomes of their services and how that affects their quality of life.

Establish Strong Quality Measures

State policymakers should include consumer-centered outcomes as part of required reporting for MCOs and make consumers a meaningful part of determining quality measures for MLTSS. States do not need to wait for federally sanctioned or nationally vetted measures. They can use state-designed measures, as well as consumer surveys such as NCI, Council on Quality and Leadership Personal Outcome Measures (POMS) or the [CAHPS HCBS survey](#). Advocates should push for quality measures that reflect outcomes that will improve overall quality of life for consumers, and urge states to expand use of consumer surveys. States using NCI should increase their survey sample size to retain validity when data is disaggregated for managed care vs FFS, or by MCO, and for demographic characteristics (such as race, gender and disability).

- **Michigan** includes outcomes in its performance indicators for managed care plans. They are required to report on the following:
 - The percent of adults who are in competitive employment.
 - The percent of adults who earn state minimum wage or more from employment activities.
 - The percent of adults who live in a private residence alone, or with a spouse or non-relative.(See Attachment P7.7.1.1 in the [Contract](#).)

Gather, Analyze and Publically Release Grievance and Appeals Data

State policymakers should require that MCOs report grievance and appeals data stratified by population and type of grievance. Officials should analyze this data at least yearly for systemic issues, publicly share the data and

analysis in an accessible format, and address the problems identified. Advocates should insist on publicly available data that is published in accessible language, and should press for systemic solutions.

Require Consumer-Centered Policies in All Aspects of MLTSS Program Design

Advocates should insist program basics are set up to best serve consumers. Our online tool, [Strengthening Long-Term Services and Supports: A Tool to Assess and Improve Medicaid Managed Care](#), provides a checklist and examples of how all MLTSS programs can best serve consumers of all backgrounds and abilities.

Start with Strong Contract Language

- **Michigan's** managed care contract includes robust policies on person-centered planning and self-determination for people with IDD (see Attachment P4.4.1.1 in the [Contract](#)). However, stakeholders say the implementation of these practices is strong in some regions and weak in others.
- **New York** requires plans in its small demonstration program for people with I/DD in Medicaid and Medicare (FIDA-IDD) to assess participants using the "It's All About Me" (IAM) [smart-phone application](#). This tool, written in person-first language, covers the following domains: social, functional, medical, behavioral, wellness and prevention, caregivers' status and capabilities, and participant's preferences, strengths, and goals. This assessment can provide a narrative about the participant's life, goals and preferences (see page 24 of the [Memorandum](#) of Understanding), to drive a comprehensive service plan that can help the person achieve those goals.

MOVING FORWARD

The problems of MLTSS programs for people with IDD have caused states to rethink managed care as the model for IDD service system reform. In Texas, the legislature ordered state officials to postpone the transition of people with IDD to commercial managed care from 2021 to 2027, and gave the LTSS agency the authority to delay deadlines further, if needed²⁵. Advocacy to protect LTSS service systems for people with IDD has been successful in several states. In 2016, consumer advocates in Wisconsin fought off a proposal to switch to commercial MLTSS²⁶, as did advocates in Arizona in 2018.²⁷

This opens up space for advocates to introduce other ideas on how to improve and strengthen the IDD service delivery system. States should dedicate many seats at decision-making tables for consumers and consumer advocates and work in partnership to develop sustainable solutions for improvement. These solutions may include nonprofit plans managing MLTSS that is fully integrated with physical and behavioral health, as well as Accountable Care Organizations or Health Homes outside of managed care that provide extensive care management across LTSS, physical and behavioral health; a focus on integration of people with IDD into the community; and better quality services for the money.

In states where officials are willing to work with advocates, advocates should demand that consumers themselves are actively and meaningfully engaged throughout all stages of program planning and implementation, and draw on lessons from other states.

In other cases, advocates should consider opposing a move to commercial managed care for people with IDD. Recent experiences show consumers suffer when states do not meaningfully seek out and integrate consumer feedback, thoughtfully transition providers and consumers to the new program, and create robust oversight mechanisms.

APPENDIX A

Managed LTSS-IDD Program Chart

State	Program Name	Year Started	Managing Entity	Degree of LTSS Integration with Health Services
Arizona	Arizona Long-Term Care System (ALTCs)	1988	Government Agency - Division of Developmental Disabilities (DDD)	Partial*
Arkansas	Provider-led Arkansas Shared Savings Entity (PASSE)	2019	Private Provider-Led Entities (51% provider ownership)	Full
Iowa	Iowa Health Link	2016	Commercial Managed Care Organizations	Full
Kansas	KanCare	2014	Commercial Managed Care Organizations	Full
Michigan	Managed Specialty Services and Supports	1998	Public Regional Managing Entities	Partial
North Carolina	Innovations Waiver	2013	Nonprofit Regional, Quasi-Governmental Managing Entities	Partial
Tennessee	ECF Choices	2016	Commercial Managed Care Organizations	Full
Wisconsin	Family Care	1998	Regional Nonprofit Managed Care Organizations	LTSS only

*will be moving to LTSS only

APPENDIX B

ANCOR: [Advancing Value & Quality in Medicaid Service Delivery for Individuals with Intellectual & Developmental Disabilities](#)

Carli Friedman, PhD, Council on Quality and Leadership, the Institute for Public Policy for People with Disabilities, and Mosaic: [Building the Framework for IDD Quality Measures](#)

Health Management Associates: [Current Landscape: Managed Long-Term Services and Supports for People with Intellectual and Developmental Disabilities](#)

NASUAD MLTSS Institute: [Collaborating to Address HCBS Workforce Challenges in MLTSS Programs](#)

NASUAD MLTSS Institute: [MLTSS for People with Intellectual and Developmental Disabilities](#)

President's Committee for People with Intellectual Disabilities: [America's Direct Support Workforce Crisis: Effects on People with Intellectual Disabilities, Families, Communities and the U.S. Economy](#)

President's Committee for People with Intellectual Disabilities: [2012 Report to the President: Managed Long Term Services and Supports](#)

ENDNOTES

- ¹ Dunkelberg, A. & Kohler, A. (July 10, 2019). Real Protections for Kids and Families in the Newest Texas Medicaid Managed Care Laws. Retrieved from <https://ccf.georgetown.edu/2019/07/10/real-protections-for-kids-and-families-in-the-newest-texas-medicaid-managed-care-laws/>
- ² Gifford, K., Ellis, E., Coulter Edwards, B., Lashbrook, A., Hinton, E., Antonisse, L., Valentine, A., Rudowitz, R. (October 19, 2017). Medicaid Moving Ahead in Uncertain Times: Results from a 50-State Medicaid Budget Survey for State Fiscal Years 2017 and 2018. Retrieved from <https://www.kff.org/report-section/medicaid-moving-ahead-in-uncertain-times-managed-care-initiatives/>
- ³ Truven Health Analytics (now IBM Watson Health). (January 29, 2018). *The Growth of Managed Long-Term Services and Supports Programs: 2017 Update*. Cambridge, MA: Lewis, E., Eiken, S., Amos, A., & Saucier, P. <https://www.medicaid.gov/medicaid/managed-care/downloads/ltss/mltssp-inventory-update-2017.pdf>
- ⁴ Health Management Associates. (June 11, 2018). *Current Landscape: Managed Long-Term Services and Supports for People with Intellectual and Developmental Disabilities*. Lewis, S., Patterson, R., & Alter, M.
- ⁵ American Association on Intellectual and Developmental Disabilities. (2019). *Frequently Asked Questions on Intellectual Disability*. Retrieved from <https://aidd.org/intellectual-disability/definition/faqs-on-intellectual-disability>
- ⁶ American Association on Intellectual and Developmental Disabilities. (2012). *Employment: Joint Position Statement of AAIDD and The Arc*. Retrieved from <https://aidd.org/news-policy/policy/position-statements/employment>
- ⁷ This is closely linked with self-determination and refers to the right of an individual to make choices about how they live their life, even if there is potential harm that accompanies that choice. An essay on this topic by a parent of a child with autism can be found here: <http://www.tennesseeworks.org/the-dignity-of-risk/>
- ⁸ University of Minnesota Institute on Community Integration. (n.d.). *Self-determination and self-direction*. Retrieved from <https://ci.ici.umn.edu/our-work/self-determination-and-self-direction>
- ⁹ Vatland, C., Strickland-Cohen, K., Loman, S., Doren, B., Herner, R., & Walker, H. (February 2011). *Promoting Self-Determination for Adults: A Practice Guide*. Retrieved from www.ngsd.org/sites/default/files/promoting-self-determination-for-adults-a-practice-guide.pdf
- ¹⁰ Health Management Associates. (June 11, 2018). *Current Landscape: Managed Long-Term Services and Supports for People with Intellectual and Developmental Disabilities*. Lewis, S., Patterson, R., & Alter, M.
- ¹¹ National Core Indicators. (2018). *NCI At-A-Glance Report 17-18*. Retrieved from the National Core Indicators Website: <https://www.nationalcoreindicators.org>
- ¹² National Core Indicators. (March 5, 2019). *In-Person Survey 2017-18 Final Report*. Retrieved from the National Core Indicators Website: <https://www.nationalcoreindicators.org>
- ¹³ Rizzolo, M. K., Larson, S., & Hewitt, A.S. (2016). Long-term supports and services for people with IDD: Research, Practice and Policy Implications. In *Critical issues in Intellectual and Developmental Disabilities: Contemporary Research, Practice and Policy*. Washington, DC: American Association on Intellectual and Developmental Disabilities.
- ¹⁴ Community Catalyst. (2012). *Putting Consumers First: Promising Practices for Medicaid Managed Long-Term Services and Supports*. Boston, MA: Dembner, A. Retrieved from https://www.communitycatalyst.org/doc-store/publications/putting_consumers_first_LTSSmanagedcare.pdf
- ¹⁵ Health Management Associates. (June 11, 2018). *Current Landscape: Managed Long-Term Services and Supports for People with Intellectual and Developmental Disabilities*. Lewis, S., Patterson, R., & Alter, M.

- ¹⁶ Medicaid and CHIP Payment and Access Commission. (June 2018). *Report to Congress on Medicaid and CHIP. Chapter 3: Managed Long-Term Services and Supports*. Retrieved from <https://www.macpac.gov/wp-content/uploads/2018/06/June-2018-Report-to-Congress-on-Medicaid-and-CHIP.pdf>
- ¹⁷ Davis, A. (April 28, 2019). Suit targets Medicaid payment delays; class-action status sought for providers of health care to 40,000 Arkansans. *Arkansas Democrat Gazette*. Retrieved from https://www.arkansasonline.com/news/2019/apr/28/suit-targets-medicaid-payment-delays-20-1/?utm_medium=email&utm_campaign=morning-4-28-19-subscribers&utm_content=morning-4-28-19-subscribers+CID_9f65f98cf99607b934d2a48083d76e29&utm_source=Email%20Marketing%20Platform&utm_term=Suit%20targets%20Medicaid%20payment%20delays%20class-action%20status%20sought%20for%20providers%20of%20health%20care%20to%2040000%20Arkansans
- ¹⁸ Leys, T. (December 6, 2017). Disabled Iowans' Medicaid lawsuit against state suffers legal setbacks. *Des Moines Register*. Retrieved from <https://www.desmoinesregister.com/story/news/health/2017/12/06/disabled-iowans-medicaid-lawsuit-against-state-suffers-legal-setbacks/928131001/>
- ¹⁹ Division of TennCare. (May 30, 2019). *TennCare II Section 1115 Quarterly Report (For the period January – March 2019)*. Retrieved from <https://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Waivers/1115/downloads/tn/TennCare-II/tn-tenncare-qrt-rpt-jan-mar-2019.pdf>
- ²⁰ Cunningham, C. (n.d.) *Applying Alternative Payment Methodologies and Value-Based Purchasing to HCBS Supported Employment Services in MLTSS Programs to Advance States' Employment First Goals*. Retrieved from <http://www.advancingstates.org/sites/nasuad/files/Alternative%20pay.pdf>
- ²¹ University of Minnesota Institute on Community Integration. (n.d.). *RISP State Profiles*. Retrieved from <https://risp.umn.edu/state-profiles>
- ²² Sisirak, J., Marks, B., Heller, T., Ronneberg, C., Ailey, S., & McDonald, K. (2016). People with IDD: Health and Wellness for All. In *Critical issues in Intellectual and Developmental Disabilities: Contemporary Research, Practice and Policy*. Washington, DC: American Association on Intellectual and Developmental Disabilities.
- ²³ Wisconsin Department of Health Services. (n.d.) FAQs: *Direct Care Workforce Funding Initiative*. Retrieved from <https://www.dhs.wisconsin.gov/medicaid/ltc-workforce-funding-faq.htm>
- ²⁴ MLTSS Institute. (n.d.). Collaborating to Address HCBS Workforce Challenges in MLTSS Programs. Snyder, Y., Pierson, D., Dobson, C. Retrieved from <http://www.advancingstates.org/sites/nasuad/files/Collaborating%20to%20Address%20HCBS%20Workforce%20Challenges%20in%20MLTSS%20Programs%202019.pdf>
- ²⁵ Dunkelberg, A. & Kohler, A. (July 10, 2019). Real Protections for Kids and Families in the Newest Texas Medicaid Managed Care Laws. Retrieved from <https://ccf.georgetown.edu/2019/07/10/real-protections-for-kids-and-families-in-the-newest-texas-medicaid-managed-care-laws/>
- ²⁶ Letter to the Wisconsin Joint Committee on Finance. Retrieved from <https://cdn.ymaws.com/ewala.org/resource/resmgr/Docs/eBlastDocs/DHSWithdrawFC-IRIS2.pdf>
- ²⁷ Division of Developmental Disabilities Integrated Health Care Choice Plans Integrated Request for Proposal. Retrieved from <https://des.az.gov/sites/default/files/media/Major-Decisions-for-Integrated-RFP-FINAL-updated-10-22-2018.pdf>