



HEALTH MANAGEMENT ASSOCIATES

Are We There Yet? Improving Quality, Care Integration and Supports for People with Intellectual and Developmental Disabilities

HCBS Conference
December 3, 2020



Are We There Yet?

Improving Quality, Care Integration and Supports for People with Intellectual and Developmental Disabilities

Today's Panel:

Kristal Vardaman, Medicaid and CHIP Payment and Access Commission

Mary Sowers, National Association of State Directors of Developmental Disabilities Services

Melissa Stone, Arkansas Department of Human Services

Liz Weintraub, Association of University Centers on Disabilities

Sharon Lewis, Health Management Associates





MACPAC Study on Medicaid Services for People with ID/DD

—
Medicaid and CHIP Payment and Access Commission

Kristal Vardaman

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www.macpac.gov

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Introduction to MACPAC

- Non-partisan, independent legislative branch agency
- Provide analyses and advice to Congress, HHS, and the states on Medicaid and CHIP policy issues
 - Report annually on March 15 and June 15
 - Provide technical assistance to Congress
 - Serve as an information resource to the broader health policy community
- 17 commissioners appointed by GAO to three-year terms
 - Meet 6–8 times per year in public
 - Permanent staff of 30 based in DC
- Began work in 2010

Why We Did This Work

- Medicaid is the largest payer of long-term services and supports (LTSS) for people with intellectual or developmental disabilities (ID/DD)
- Discussions of LTSS sometimes overlook differences in needs of and services provided to different groups of people who use LTSS
 - People with ID/DD have varied needs, both across individuals and across their lifespan
- There is growing interest in care models that improve how Medicaid serves people with ID/DD while managing costs
 - Managed long-term services and supports (MLTSS)
 - Integrated care models for people who are dually eligible for Medicare and Medicaid

Methods

- Literature review
- Stakeholder interviews
 - people with ID/DD
 - state Medicaid officials
 - state developmental disabilities agency officials
 - health plans
 - federal official
 - associations representing providers of ID/DD services
 - consumer organizations

Selected Findings

- People with ID/DD are a heterogeneous population who rely on a wide range of LTSS
- More data and research are needed on people with ID/DD who belong to racial, ethnic, and linguistic minority groups, as well as more culturally responsive supports and services
- Policies have expanded access to home- and community-based services (HCBS) in recent decades, but HCBS waiver waiting lists still exist in many states
- There is movement to implement and operationalize more person-centered thinking, planning, and practice

Selected Findings (continued)

- There is a trend toward self-direction, this approach is most effective when people get appropriate supports to manage their plans and services
- States are increasingly supporting families of people with ID/DD
- Workforce issues are a challenge
 - Shortage of direct care workers
 - Need for better training for physicians, dentists, and behavioral health providers to meet needs of people with ID/DD
- The COVID-19 pandemic has posed a high risk for people with ID/DD, with elevated risk for people of color

Conclusions

- Efforts to further rebalance LTSS and implement MLTSS should acknowledge the unique needs of people with ID/DD
- Successful state innovations should be disseminated and replicated
- Additional work is needed to better understand key issues
 - Direct care and clinical workforce issues
 - Behavioral health supports
 - Equity issues and health disparities

MACPAC Resources

- Health Management Associates report will be publicly released in January, including an accessible version
- June 2018 issue brief: *Medicaid Home and Community-Based Services: Characteristics and Spending of High-Cost Users.*
<https://www.macpac.gov/publication/medicaid-home-and-community-based-services-characteristics-and-spending-of-high-cost-users/>
- June 2018 chapter: *Managed Long-Term Services and Supports: Status of State Adoption and Areas of Program Evolution.*
<https://www.macpac.gov/publication/managed-long-term-services-and-supports-status-of-state-adoption-and-areas-of-program-evolution/>
- Additional resources:
 - <https://www.macpac.gov/topics/long-term-services-and-supports/>
 - <https://www.macpac.gov/subtopic/home-and-community-based-services/>

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In most states, Medicaid-funded I/DD systems are largely rebalanced away from institutions, but many people continue to wait for home and community-based services or have limited choices.

What are best or promising practices to both improve access to services and supports, and to promote self-determination for people with I/DD?

Question 1:

What are best or promising practices both to improve access to services and supports, and to promote self-determination for people with ID/DD?

- States reviewing the use of supports waivers to offer varying levels of support in order to reach more individuals
- States are seeking to expand relationship-based services to ensure more individualized, community based options
- Many states are interested in expanding the use of self-direction – including the supports necessary to help individuals be successful

Question 1

What are best or promising practices both to improve access to services and supports, and to promote self-determination for people with ID/DD?

- Brief Discussion of the PASSE model in Arkansas
- New Community Support Systems Provider Type for Tier II and III
 - Dually diagnosed members with BH and IDD needs
 - Community and Employment Supports Waiver Waitlist

Q1: Improving Services, Promoting Self-Determination

Choice and Control:

- Let us choose, train, and manage staff
- Listen to us, not just families!
- Support us to make our own decisions, even when there is disagreement

Role of Providers:

- Help us connect to people and activities important to us – including people without disabilities
- Worry less - it's OK for us to make mistakes!





Across the country, full integration of medical care and behavioral health care with I/DD HCBS in a coordinated manner is fairly limited. We also know that many people have concerns about pushing HCBS towards a medical model.

What can Medicaid systems do to improve coordination and integration of care for people with I/DD, while maintaining a focus on holistic quality of life outcomes?

Question 2:

What can Medicaid systems do to improve coordination and integration of care for people with ID/DD, while maintaining a focus on holistic quality of life outcomes?

- Improve information and data sharing – **when appropriate** – between individuals and families and the professionals that support them.
- Use data to make good system decisions
- Make certain the paradigm is set in stone that the medical services do not define or dictate but instead inform and support community integration – Have these conversations intentionally at a system and individual level
- Make information and data easier for the individual to understand and control. Healthcare can be unnecessarily complex – helping individuals be in the drivers seat will start with making information understandable

Question 2

What can Medicaid systems do to improve coordination and integration of care for people with ID/DD, while maintaining a focus on holistic quality of life outcomes?

- Further expansion on response to question #1
- Use of functional independent assessment
- Breaking barriers between medical models and HCBS models

Q2: Care Integration and Quality of Life

Medical providers:

- Not enough doctors who know how to work with us
- Doctors and nurses need to talk to us, not just family/supports
- They need to share information in ways we can understand

Keeping the focus on what's important:

- Health and safety are important but so is happiness and belonging
- Supporting self-determination helps people be healthy and have a good quality of life

HCBS to support a good life:

- Services should come to people in their lives and community – people should not have to go to providers for services
- We need to have friends and relationships with people without disabilities





This year has been dominated by COVID-19, as well as bringing issues related to equity and racial justice to the forefront.

How will 2020 change I/DD services for the future?

Question 3:

This year has been dominated by COVID-19, as well as bringing issues related to equity and racial justice to the forefront. How will 2020 change ID/DD services in the future?

- 2020 has shown that person-centered practices are not “nice to do” but are “necessary to do” – planning and arranging supports has to be based on individuals preferences and I hope that these practices (solidified during a time of crisis) stick
- This year has also shown a path where states and providers can think about services in a different way than they have in the past – using technology to foster (not replace!) community integration and using small, more individualized approaches to supports
- Recognition that health is important – not to swing back to a medical model but to recognize that health is essential to a good community life
- Recognition of the pivotal role DSPs play in our service system

Question 3

This year has been dominated by COVID-19, as well as bringing issues related to equity and racial justice to the forefront. How will 2020 change ID/DD services in the future?

- What Arkansas learned about telemedicine
- The benefit of well checks
- Good Neighbor Project

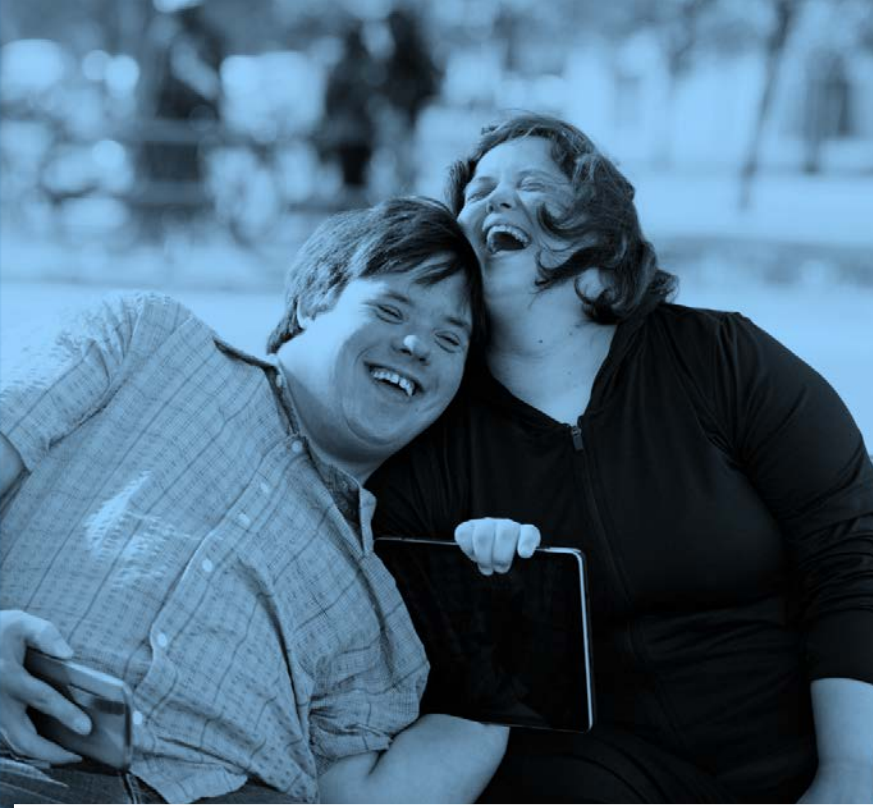
Q3: Looking forward, after 2020

- People with I/DD face a lot of risk if they get sick with COVID
- We need more data and information about what is happening to people with I/DD who get COVID
- Many people are very isolated and lonely
- We have a lot of work to do to make the system fair for everyone

Lessons learned in 2020:

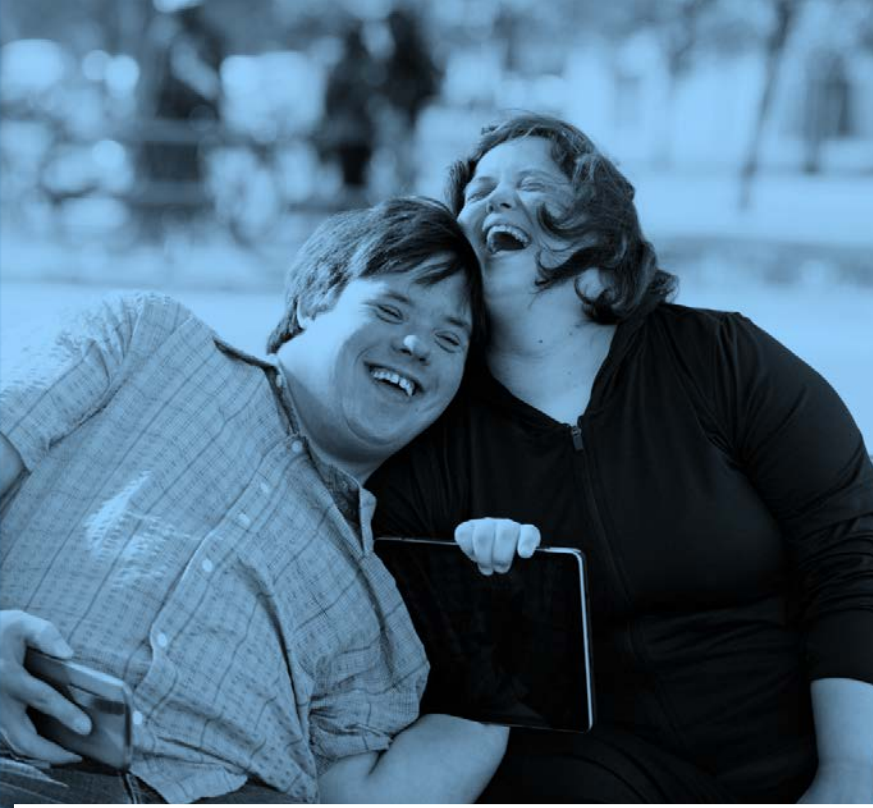
- ALL means ALL – we all need access to medical treatment and supplies, in fair ways
- When we think about inclusion, we need to consider everyone, and do a better job including people from different races and cultures
- Technology and communication options need to be available to everyone
- Relationships matter – they help keep people healthy and happy





Q&A: Please use “chat” function to submit questions





Thank you!

