



# Supporting Adults with Intellectual and Developmental Disabilities (I/DD) and Their Aging Caregivers



*Post-Summit  
Webinar*

*October 12, 2021*

# Ice Breaker



Where are you joining  
us from today?

**Please enter your  
location in the chat!**

# Agenda

- Welcome and Logistics
- Overview of Adults with I/DD
- Strategies for Supporting Adults with I/DD and Their Aging Caregivers
- Next Steps

# Logistics

The screenshot shows a Zoom Meeting window with the following details:

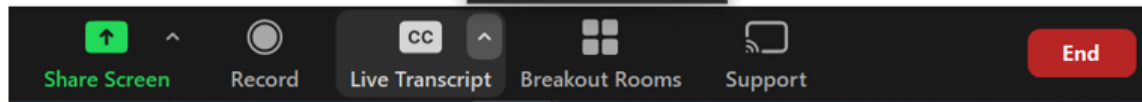
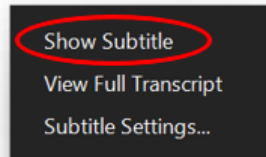
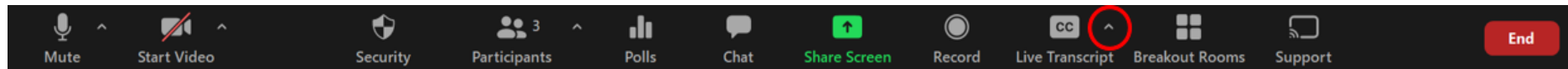
- Talking:** Victoria Heller
- Meeting Topic:** Victoria Heller's Zoom Meeting
- Host:** Victoria Heller
- Password:** 282774
- Invite Link:** <https://zoom.us/j/96746463997?pwd=c0RKK0Ztb2FQVVEw...>  
[Copy Link](#)
- Participant ID:** 294381

At the bottom of the window, there is a toolbar with several icons. Annotations with blue arrows point to these icons:

- Mute/Unmute Speakers:** Points to the Mute icon (a microphone with a slash).
- Turn Video On/Off:** Points to the Start Video icon (a video camera).
- Open Chat Pod:** Points to the Chat icon (a speech bubble).
- Share Screen:** Points to the Share Screen icon (a screen with a green arrow).
- Closed Captions:** Points to the CC icon (a speech bubble with a plus sign).

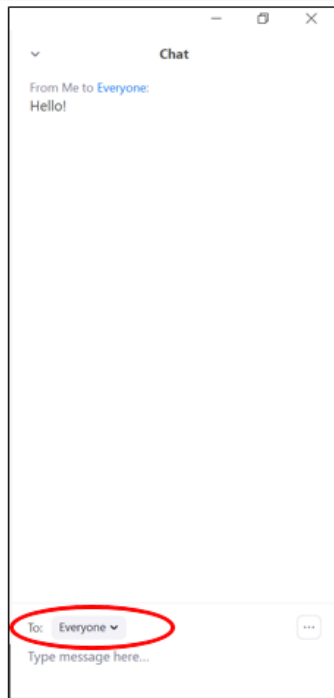
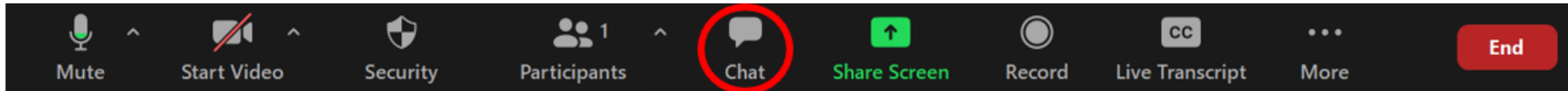
The 'Mute' and 'Start Video' icons are circled in red. The 'Chat' icon is also circled in red, and a red oval highlights the 'Test' text in the chat window above it.

# Turn on Closed Captioning



- To turn on closed captioning, click the caret on the top right of the “Live Transcript” box
- A pop-up box should appear. Select “Show Subtitle” to turn on closed captions

# Let's Chat!



- Use the Chat pod to submit any questions or comments
- Please use “@” if your question/comment is directed to a specific presenter
- Click on the “Chat” button to open the Chat pod
- Submit your question/comment by clicking the enter button on your keyboard once you have finished typing

# Disclaimer

The information and practices shared during this webinar may not be validated or evidence-based. They are intended to initiate discussion and raise awareness of various approaches and challenges around the webinar topic and are in no way a form of endorsement by the Centers for Medicare & Medicaid Services (CMS). This webinar is presented by CMS, but is not presenting CMS recommendations or CMS policy.



## Welcome from CMS and ACL

*Alissa Mooney DeBoy,  
Director, Disabled and Elderly  
Health Programs Group  
Center for Medicaid and CHIP  
Services  
Centers for Medicare &  
Medicaid Services (CMS)*

*Jennifer G. Johnson, Ed. D.  
Deputy Commissioner,  
Administration on Disabilities  
Director, Office of Disability  
Service Innovations,  
Administration for Community  
Living (ACL)*



# Technical Expert Workgroup (TEW)

## TEW Members

<b>Todd Wilson</b> , CMS	<b>Mary Sowers</b> , NASDDDS
<b>Dianne Kayala</b> , CMS	<b>Kelly Eifert</b> , South Carolina Department of Health and Human Services
<b>Martha Egan</b> , CMS	<b>Margaret Alewine</b> , South Carolina Department of Health and Human Services
<b>Jennifer Johnson</b> , Administration for Community Living, Administration on Disabilities	<b>Andrea Juris</b> , New York State Department of Health (Money Follows the Person)
<b>Greg Link</b> , Administration for Community Living, Administration on Aging	<b>Deborah Waymer</b> , New York State Office for People With Developmental Disabilities (Money Follows the Person)
<b>Walker Tisdale</b> , Substance Abuse and Mental Health Services Administration	<b>Patricia Sastoque</b> , Maryland Developmental Disabilities Administration

# Supporting Adults with I/DD and Their Aging Caregivers- Activities



# Supporting Adults with I/DD and Their Aging Caregivers Summit

- Over 140 participants joined the three-session Summit held June 28-29, 2021 to:
  - Convene with other stakeholders, including state and federal agency representatives
  - Discuss current needs and interests related to supporting adults with I/DD and their aging caregivers
  - Share resources and promote learning

# Summit Themes

- During the Summit, the following elements emerged as central to state Medicaid and partner agencies successfully supporting adults with I/DD and their aging caregivers:
  - Person- and family-centered supports
  - Interagency partnerships and relationships
  - Engagement and navigation supports
  - Cultural and linguistic competence
  - Future planning, including supported decision making

# Post-Summit Webinar Goals

Learn about promising practices and challenges

Share and discuss actionable strategies

Learn about upcoming opportunities



# Adults with I/DD: An Overview



*Erika Robbins,  
Vice President,  
The Lewin Group*

# Adults with I/DD

- In 2017, there were an estimated 7.38 million people with I/DD in the U.S.<sup>1</sup>
  - Only 20 percent (1.48 million) of people with I/DD were known to, or served by, state I/DD agencies<sup>1</sup>
- The number of people with I/DD using home and community-based services (HCBS) and living with family increased by 134 percent between 1998 and 2017<sup>1</sup>
- As adults with I/DD and their caregivers age and face life transitions, they face new challenges and may need new or additional supports

# Challenges Faced by Adults with I/DD

- Adults with I/DD live, work, have friends, and participate in the community; however, they also face challenges, including:
  - Higher levels of chronic health and mental health conditions
  - Lower rates of employment
  - Barriers to appropriate housing
  - Finding and maintaining direct service support
- Research suggests that Latinx and Black adults with I/DD experience worse health outcomes than White adults with I/DD<sup>2</sup>

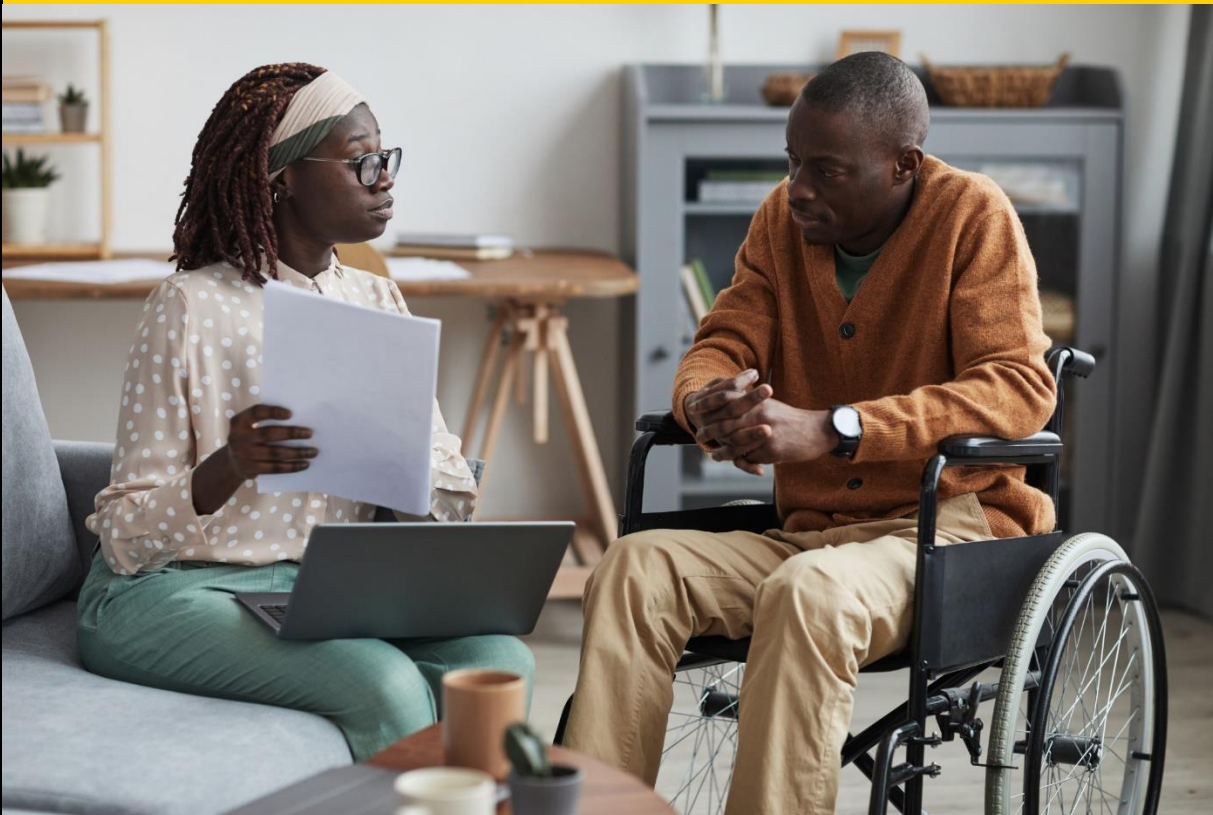


# Supporting Adults with I/DD and Their Aging Caregivers

- An estimated one million households in the U.S. include an adult with I/DD living with and supported by an aging caregiver, and this number is growing<sup>3</sup>
  - Of adults receiving long-term services and supports (LTSS) through their I/DD agency, 60 percent live at home with family<sup>1</sup>
- Most family members supporting an adult with I/DD are parents (87 percent)<sup>4</sup>
  - Most caregivers of adults with I/DD are age 55 and older<sup>4</sup>

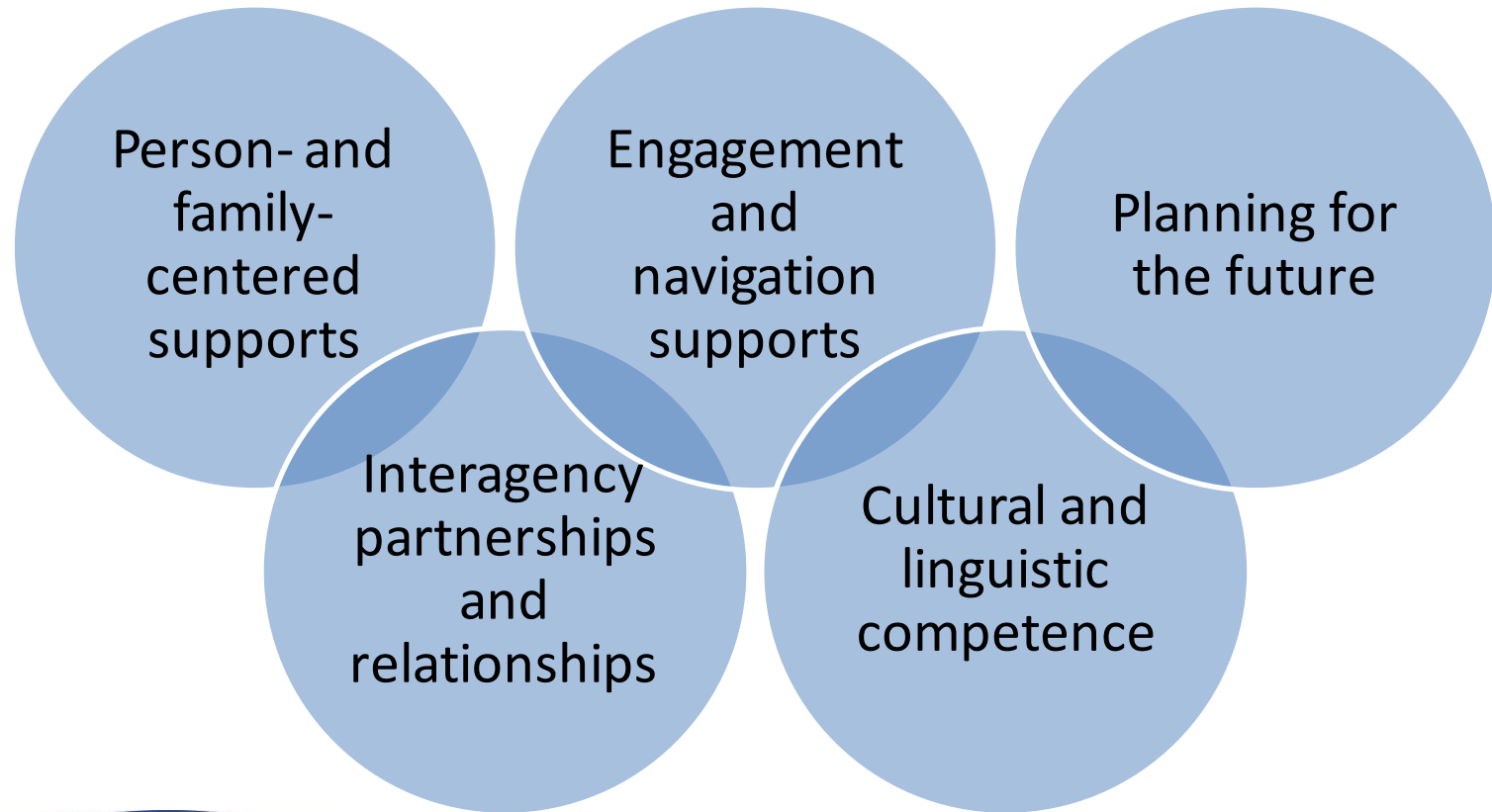


# Strategies for Supporting Adults with I/DD and Their Aging Caregivers

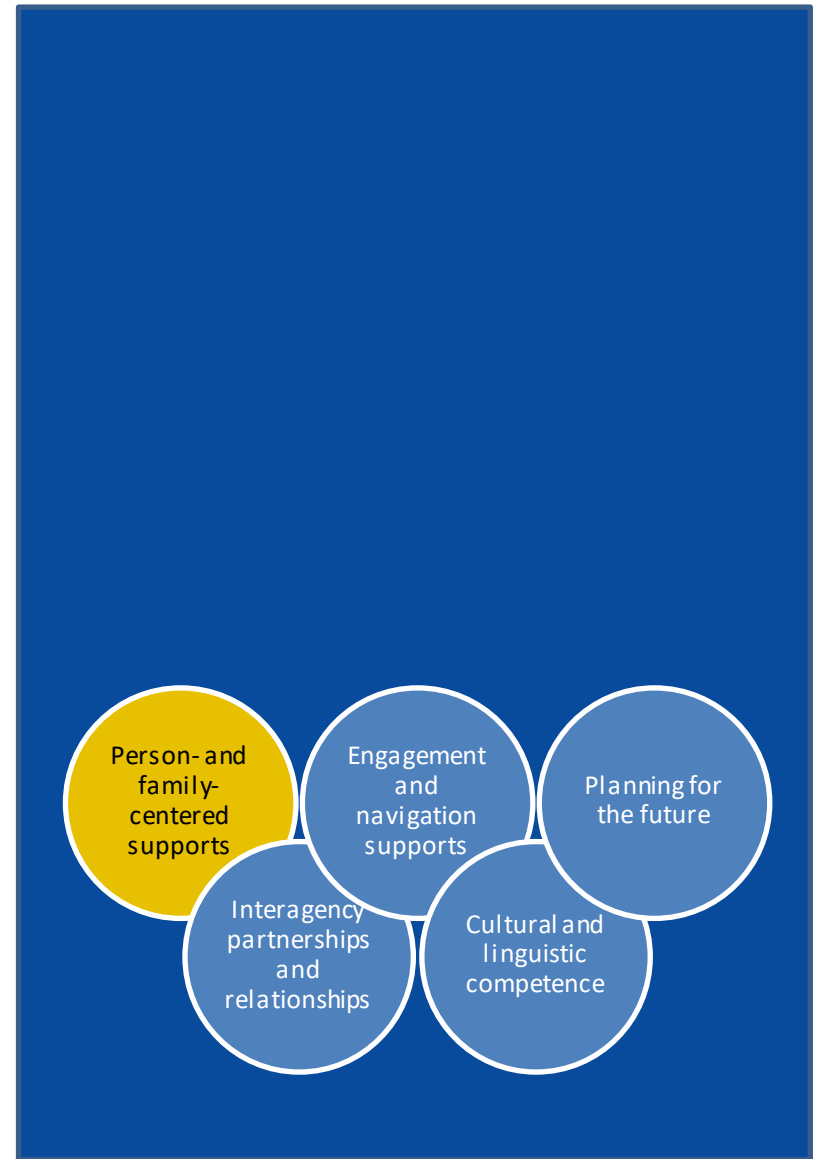


*Mary Sowers, Executive Director,  
Barbara Brent, Director of State Policy,  
National Association of State Directors of Developmental Disabilities Services*

# Key Elements for Supporting Adults with I/DD and Their Aging Caregivers



# Person- and Family-Centered Supports



# Person- and Family-Centered Supports

- Person- and family-centered supports are particularly important during periods of transition for adults with I/DD and their aging caregivers
- Person- and family-centered strategies for state Medicaid and partner agencies to facilitate life stage transitions:
  - Start ongoing conversations about the future early, including where the individual and family see the individual living and working
  - Engage siblings early as partners in planning to determine if and how they would like to be involved in the future
  - Promote relationships with others in the community (e.g., faith communities, work, cultural groups, volunteering) for both the individual and the aging caregiver



# State Spotlight: Washington



***Jaime Bond,  
Office Chief, Program  
and Policy Development,  
Washington Department  
of Social and Health  
Services***



***Teresa Boden,  
Office Chief, Quality and  
Compliance Unit,  
Washington Department of  
Social and Health Services***



***Jeremy Norden-Paul,  
Executive Director,  
Washington State  
Developmental Disabilities  
Council***

# Q/A with Washington



# Interagency Partnerships and Relationships





# Interagency Partnerships and Relationships (1/2)

- Partnerships between state Medicaid and state I/DD agencies help ensure a comprehensive long-term services and supports (LTSS) and health system for individuals with I/DD and their families in the community
- To better support individuals with I/DD across the lifespan, state Medicaid agencies and I/DD agencies build bridges with other partners in state government at each juncture of life (e.g., early intervention, education, vocational rehabilitation, mental health, aging)
  - Reduces fissures within the system
  - Enables a person- and family-centered approach to supports

# Interagency Partnerships and Relationships (2/2)

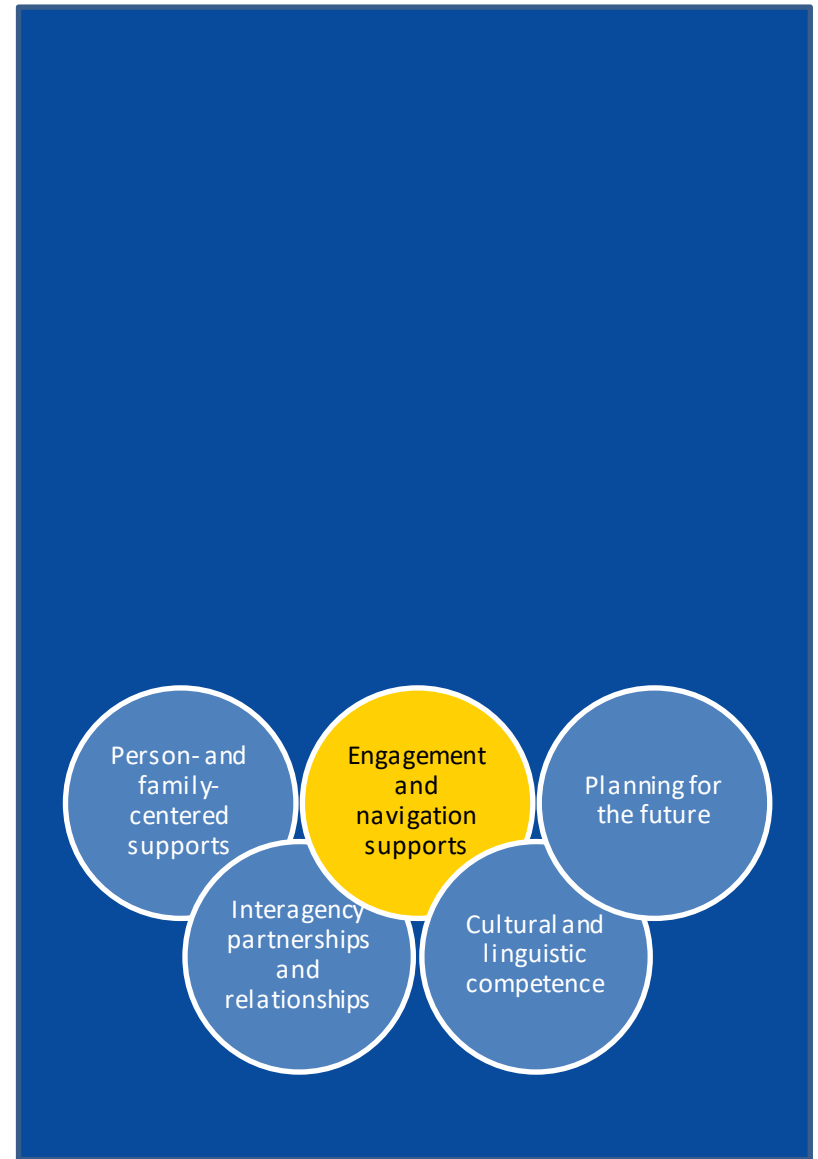
- State Medicaid, I/DD, and partner agencies support individuals with I/DD and their families for many years, often decades, through life transitions and as needs change over time
  - Over time, families may receive supports from multiple agencies (e.g., aging caregiver receiving supports from aging system, individual receiving supports from I/DD system)
- States can improve their ability to support individuals with I/DD and their families while honoring the needs of both through:
  - Stronger cross-agency partnerships
  - Greater use of Medicaid flexibilities, particularly opportunities to design waiver programs that serve more than one target group

# Discussion Question

What is one area you would like to improve in your state related to interagency partnerships?



# Engagement and Navigation Supports



# Engagement and Navigation Supports

- Comprehensive outreach and education can help state agencies engage with families before there is a crisis
  - States can include priority placement for individuals with aging caregivers on waiting lists for Medicaid HCBS waiver programs
- Engaging with families in an advisory capacity can be a valuable source of feedback and guidance for state agencies
- Peer-to-peer support can facilitate navigation of services
  - Peer-to-peer support is of value for both individuals and families to talk with someone else “who has been there” to share their concerns and ideas, share resources, and learn about navigation strategies



# State Spotlight: Pennsylvania



***Jeremy Yale***

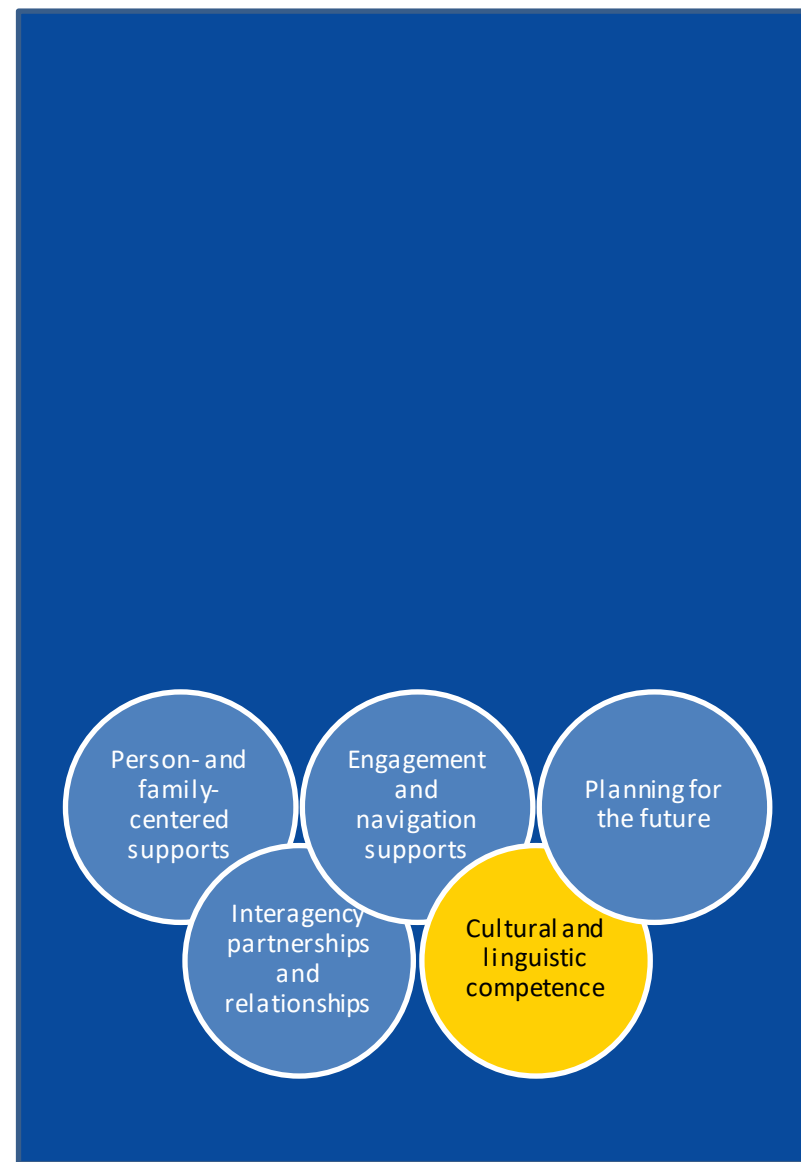
***Director***

***Office of Developmental  
Programs, Bureau of Policy  
and Quality Management,  
Pennsylvania Department of  
Human Services***

# Q/A with Pennsylvania



# Cultural and Linguistic Competence





# Cultural and Linguistic Competence

## (1/2)

- Individuals with I/DD and their families reflect diverse racial, ethnic, linguistic, and cultural backgrounds
  - Influences how individuals and families approach services
  - Shapes preferences for how supports are provided
- State Medicaid agencies and their partners must understand the cultural and linguistic backgrounds of individuals and families to ensure effective strategies for outreach, engagement, and service provision
  - Provide targeted outreach
  - Ensure accessibility of information

# Cultural and Linguistic Competence (2/2)

## Cultural Competency in D.C.

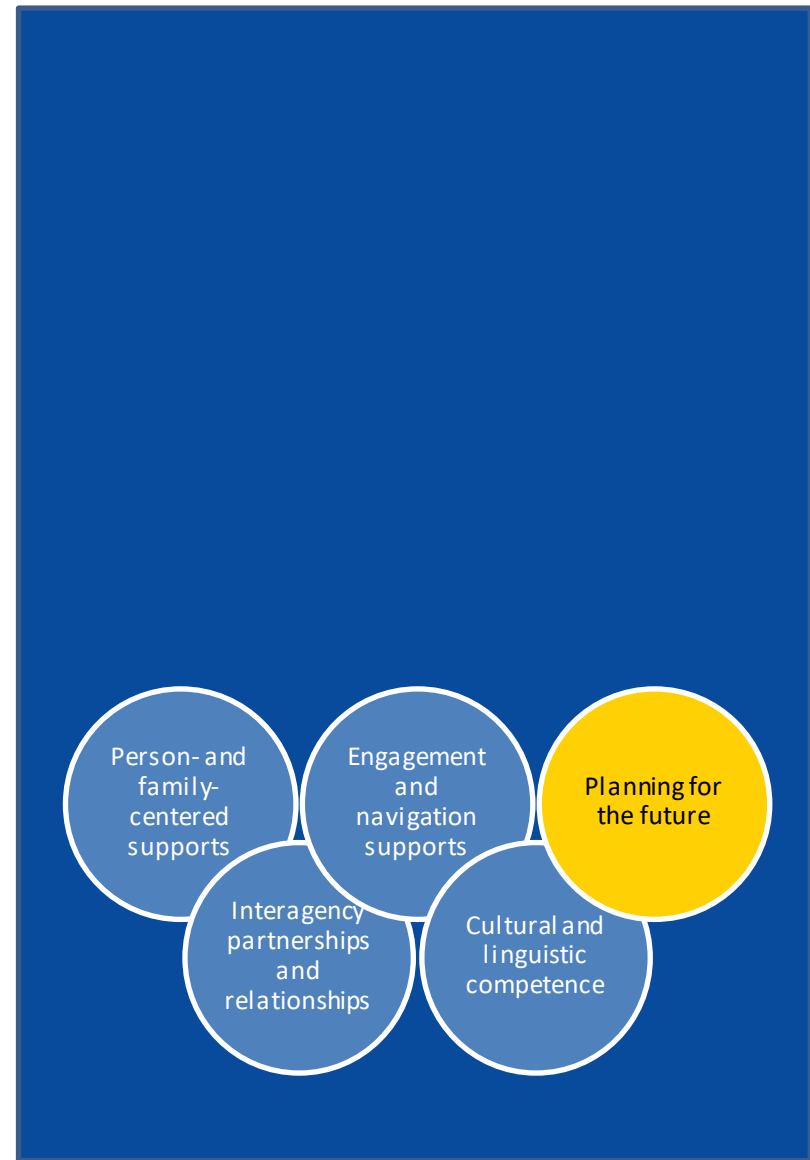
- The District of Columbia (D.C.) is expanding the reach of engagement and relationship building with underserved populations (including caregivers) by:
  - Establishing trust, common values, and shared vision for the future as a coordinated system and community
  - Viewing families as the content experts of their own lives and the lives of their family members
  - Continuously building relationships and trust
  - Beginning all program development and implementation through the lens of equity

# Discussion Question

What strategies do you use in your state to promote cultural and linguistic competence in services for individuals with I/DD and their families?



# Planning for the Future



# Planning for the Future

- Support needs change over time as individuals with I/DD and their caregivers age (e.g., medication side effects change as people with I/DD grow older, new support needs emerge as caregivers' health declines)
- Planning for the future requires state Medicaid agencies and their partners to think holistically about the individual and family and to anticipate changing needs across the lifespan
  - Consider how life transitions for both the individual with I/DD and the family caregivers will affect family life and support needs
  - Embed holistic, family-centered planning into state processes

# Planning for the Future

- State Medicaid and partner agencies can support future planning by anticipating major life and financial changes, such as retirement of a caregiver
  - Include short-term financial considerations in addition to long-term financial planning
  - Ensure continuity of providers and consider financial status adjustments

# Supported Decision Making (1/2)

- Supported decision making (SDM) is one alternative to guardianship, wherein individuals retain their right to make decisions for themselves, with the support of trusted friends and family members they choose<sup>5</sup>
  - SDM involves tools and practices that assist individuals identify the types of support they need and how to seek that help
  - SDM is person-centered and based on the knowledge that different people need different kinds or levels of help
- SDM can empower individuals to make their own decisions about HCBS and plan for their future

# Supported Decision Making (2/2)

## SDM in Tennessee and Oregon

- **Tennessee's** Employment and Community First CHOICES, part of their 1115 demonstration, includes a Decision Making Supports service to provide help understanding options to protect the rights and freedom of adults with disabilities, while providing the support they need to make decisions
- **Oregon** recently passed a bill (HB 2105) that requires that SDM be explored before appointing a guardian and that schools provide training and information regarding SDM when post-school outcomes are discussed



# Poll and Discussion

- Today's webinar presented five key elements for supporting adults with I/DD and their aging caregivers. On which of these elements are you most likely to take action in the coming weeks or months? *Respond to the poll.*
  - Person- and family-centered supports
  - Interagency partnerships and relationships
  - Engagement and navigation supports
  - Cultural and linguistic competence
  - Planning for the future
- What action do you plan to take to better support adults with I/DD and their aging caregivers? *Enter your response in chat.*



# Next Steps

- Consider implementing some of these approaches and ideas in your state
- Join the *Supporting Adults with I/DD and Their Aging Caregivers* Learning Collaborative
  - Peer-to-peer learning and sharing among state Medicaid and partner agencies:
    - Develop new solutions and identify existing practices to improve the delivery of supports and services for people with I/DD and their aging caregivers
    - Six monthly sessions starting November 2, 2021

**Thank you!**



# Sources

1. Larson, S.A., Eschenbacher, H.J., Taylor, B., Pettingell, S., Sowers, M., & Bourne, M.L. (2020). In-home and residential long-term supports and services for persons with intellectual or developmental disabilities: Status and trends through 2017. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration. Retrieved from <https://risp.umn.edu/>.
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4. National Core Indicators. (2019). *2018-19 National Adult Family Survey Final Report*. Retrieved from [https://www.nationalcoreindicators.org/upload/core-indicators/AFS\\_2018-19\\_FINALupdate\\_1\\_17.pdf](https://www.nationalcoreindicators.org/upload/core-indicators/AFS_2018-19_FINALupdate_1_17.pdf).
5. Administration for Community Living. (2021). Supported Decision Making Program. Retrieved from <https://acl.gov/programs/consumer-control/supported-decision-making-program>