

Addressing the Health Care Needs of People with Intellectual and/or Developmental Disabilities (I/DD)

WEBINAR

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Goals for Today's Webinar



Understand the health needs of people with intellectual and/or developmental disabilities (I/DD)



Identify key features of inclusive clinical care models



Examine how coverage and payment can expand access to inclusive health care

Speakers



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What is Inclusive Health?

To Special Olympics, Inclusive Health means that people with intellectual and developmental disabilities (I/DD) have equitable access to health services. The health services should be of good quality. People with I/DD should be able to afford the services, or pay for them without hardship.

It also means that people with I/DD are empowered to take an active role in deciding their health and life choices. This helps people with I/DD to be as healthy as they can be.

To make inclusive health a reality we must address unfair health differences that exist. This involves making sure that people with I/DD have easier access to health services that are adapted to meet their needs.



People with I/DD and Their Health Care Experiences

There are an estimated **10-16 million people with I/DD** that have range of health care needs.

Health care costs for this population are high, and barriers to access likely contribute to **higher health care costs**.

People with I/DD experience **disproportionate difficulties** in getting high quality, person-centered care.

These factors contribute to people with I/DD experiencing **poorer health outcomes** than the general population.



Conversation with Lannea Carter

Can you tell us a little bit about yourself, and what you do with Special Olympics?

Today we are talking about health care services, and how to make them better. What are things you like about going to the doctor, and what are hard things about going to the doctor?

If you could tell doctors and others that work with them how to make your experience better next time, what would you say?

What do you wish doctors and others that work with them understood better about you and your needs?

Is there anything else you would like to tell us about how to make health care better for people like you who have had these experiences?

Inclusive Health Care Model is Possible and Scalable with the Right Ingredients



INGREDIENTS OF INCLUSIVE HEALTH



MINIMUM VIABLE CARE MODEL:

some of each important ingredient

IDEAL CARE MODEL

includes more of each ingredient, which improves Inclusive Health

Key Ingredients – Sufficient Time with Patients

- Clinicians need more time for visits and doing care plans.
- More time for visits would improve communication, understanding patient needs and preferences, trust, and comfort.
- More time for care planning would allow tailoring the plan for a patient's specific needs and coordinating with caregivers and other providers.



Key Ingredients – Training and Empowerment



- Staff need training to understand specific needs of individuals with I/DD.
- Training prepares staff to safely handle unexpected or complex patient situations.

Key Ingredients – Accommodations

- Accommodations help ensure people with I/DD can access in-person services in a welcoming environment.
- The goals of accommodations are accessibility, comfort, and timeliness.
- Key accommodations include the physical and built environment, equipment, workflows, digital supports, and specific treatments.
- Technology can facilitate telehealth, virtual care, and timely consultation.
- It's important to involve patients and caregivers in co-designing clinic spaces and workflows.



Key Ingredients – Partnerships and Teams



- Good outcomes depend on team-based models, partnerships with other clinical groups, and working with community-based organizations.
- Other important partners include durable medical equipment suppliers, social workers, dietitians, and patient educators.

Key Ingredients – Inclusive Attitudes

- Inclusive care begins with inclusive attitudes.
- Providers need to understand stigmas and outdated assumptions.
- Inclusive attitudes support better communication, trust, and decision-making.
- Practices should use communication approaches that respect the individual with I/DD and their preferences in shared or supported decision-making. This includes welcoming caregivers and understanding their roles, needs, and expertise.
- Learning about people with I/DD – both in care settings and through other events and opportunities – are ways to build familiarity and develop more inclusive attitudes.



Key Ingredients – Other Resources and Supports



- Addressing social drivers of health (i.e., transportation needs).
- Offering support and resources to patients and caregivers (i.e., navigating services or understanding out-of-pocket costs).



Paying for Inclusive Health Care Models

Common Challenges in Funding Inclusive Health Models

Time-driven coding,
hindering longer visits

Lack of payment for
administrative tasks

Complex billing rules for
longer visit codes

Low payment levels for
codes necessary for
services needed by
people with I/DD

Lack of payment to
make upfront
investments for
infrastructure and
staffing

Lack of support from
the practice's parent
organization

What Do Additional Funding Sources Look Like Today?



- ✓ Incentive payments for quality results or for contributing to lower costs (e.g., shared savings under accountable care organizations [ACOs])
- ✓ Subsidies or zero-interest loans (e.g., from the parent health system)
- ✓ Grants and donations
- ✓ Medicaid health home payments
- ✓ Other designated funds from Medicaid agencies
- ✓ Out-of-network payments
- ✓ Out-of-pocket payments



Specialized Model Example

Kramer Davis Clinic served adults and teens with complex I/DD.

- The clinic offered comprehensive services including medicine, dentistry, psychiatry, and behavioral health, as well as physical, occupational, and speech therapy. They also work with schools and other community services.
- The facility was designed specifically to have a welcoming environment with glass doors at the entrance and two sensory rooms to promote relaxation or behavioral reward. All the exam rooms have accessible equipment.
- Kramer Davis negotiated an arrangement with their local Medicaid plan to include an upfront payment to cover services for their patients with I/DD that are outside of FFS billing, averaging about \$5,000 per month per patient. With this upfront payment, Kramer Davis estimated a 44% reduction in healthcare spend for patients. The savings were based on reductions in emergency department and inpatient care.

Steps Needed to Improve Payment



Develop better ways to identify people with I/DD



Use population health approach that considers the range in needs across people with I/DD



Develop standards for inclusive health models – both minimum and robust model



Pilot payment models to support learning and scale



Engage self-advocates and family in design and implementation

The 10 million-plus Americans with I/DD have a range of needs and their care can be complex.

More comprehensive, integrated care and innovative payment models offer promise for improving outcomes and increasing efficiency.

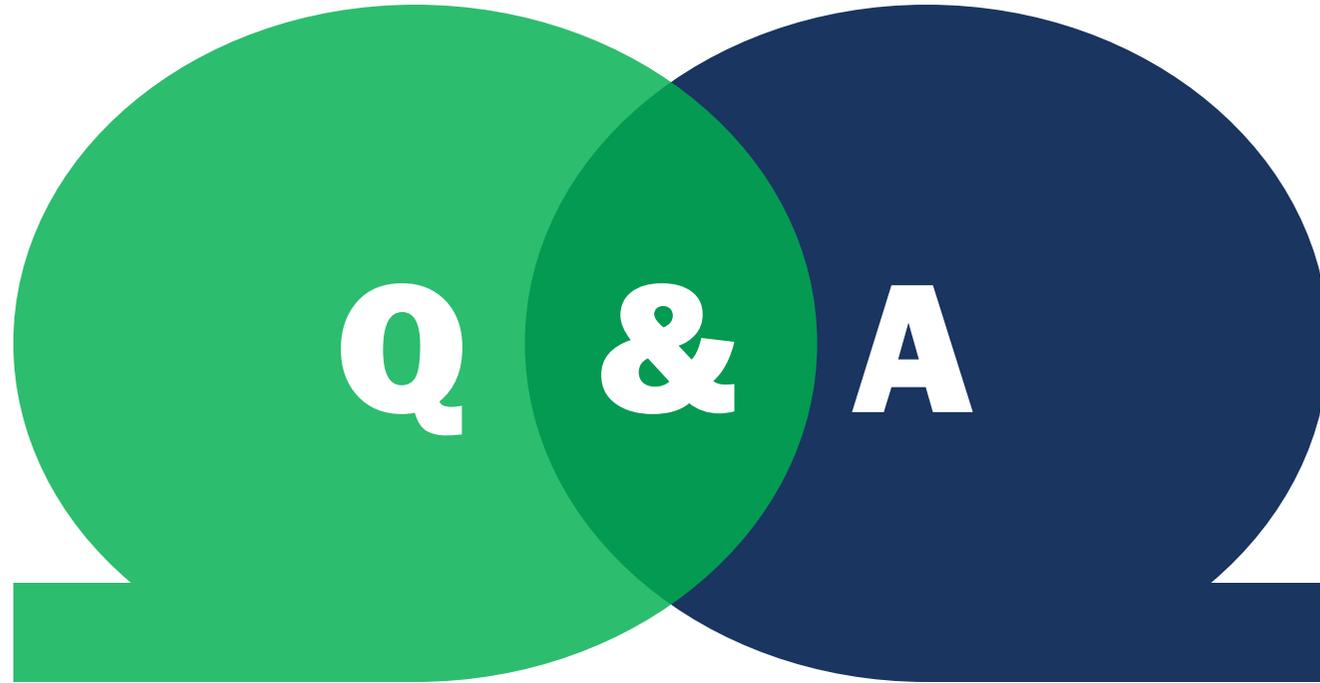
At the heart of success for these models is the commitment to listen to and partner with patients and families.

Mentioned by Panelists

- [Special Olympics Rosemary Collaboratory Initiative](#)
- [Special Olympics Inclusive Health](#)
- [Leavitt Partners Policy Brief on Addressing the Health Care Needs of People with IDD](#)
- [Leavitt Partners White Paper on Coding, Coverage, and Payment to Improve Inclusive Health](#)

Mentioned by Attendees

- [Inequities in Healthcare for People with Disabilities](#), National Center for Dignity in Healthcare and Community Living for People with Disabilities
- Dr. Lisa Iezzoni's publications on health care provider bias and disability:
 - [What some physicians say about caring for patients with disability: Responses to open-ended question to nationwide physician survey](#), Disability and Health Journal (July 2024)
 - [Physicians' Perceptions of People with Disability And Their Health Care](#) (February 2021), Health Affairs



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