ADVOCATING FOR QUALITY MEDICAID SERVICES AND SUPPORTS 2014 UPDATE

May 22, 2014

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United Spinal Association

Mission: To improve the quality of life of all people living with spinal cord injuries and disorders (SCI/D). Today, United Spinal is the largest non-profit organization dedicated to helping people living with SCI/D. We are committed to providing active-lifestyle information, peer support and advocacy that empower individuals to achieve their highest potential in all facets of life.

National Association of States United for Aging and Disabilities (NASUAD)

Mission: To design, improve, and sustain state systems delivering home and community based services and supports for people who are older or have a disability, and their caregivers.
Thank You to Our Sponsors
June 22-25, 2014

United Spinal Association’s Annual Legislative and Advocacy Conference

- United Spinal’s Public Policy department
- NSCIA – United Spinal’s Membership and Chapter division
- Users First – United Spinal’s grassroots advocates division

You can find more information at:
http://www.unitedspinal.org/events/roll-on-capitol-hill/
Upcoming Webinars

June 17 - Transitioning into Adulthood with SCI/D
Lawrence C. Vogel, MD - Shriners Hospitals for Children and Rush Medical College 1-2 pm ET

July 24 - Fight to Improve Wheelchair Access in NYC and Its National Implications
James Weisman, United Spinal Association and Margi Trapani, Center for Independence of the Disabled, New York's (CIDNY) 3-4pm ET

http://www.spinalcord.org/webinar-archive/
To ask a question or make a comment, please type in the “Questions” box
2014 Medicaid Advocate Update

• Home and Community Based Services (HCBS)
  • What they are, how to access them, how to get your state to provide quality services and supports

• Managed Care
  • What it is, how to advocate for quality managed care, and a success story

• Quality Measures
  • Why they matter, and an update on a new pilot project

• Stay Tuned: New Legislation to support HCBS
Medicaid Home and Community Based Services Overview – What are they?

• Can include
  Personal Attendants, Housing Modifications, Physical or Occupational Therapies …

• Can support
  • Living where you want to live
  • Employment
  • Contributing and participating in the community

• Can Provide Access to Necessary Medical Equipment and Devices
  • Wheelchairs, Assistive Technology and Prosthetics
Medicaid Home and Community Based Services Overview – What are they?

• Services often acquired through a state Medicaid Waiver, rehabilitation habilitation and devices through new marketplace plans

• Waivers first became available in 1983.
  • Congress added section 1915(c) to the Social Security Act, giving States the option to receive a waiver of Medicaid rules governing institutional care.
  • Waivers can be geared toward specific populations and have waiting lists

• In 2005, HCBS became a formal Medicaid State plan option.

• 47 States and DC are operating at least one 1915(c) waiver. Other HCBS Waivers – 1915(i), 1915(c), 1915(k)
Medicaid Home and Community Based Services Overview – Funding

- ~9M non-elderly individuals with disabilities rely on Medicaid
- ~4M rely on Medicare/Medicaid
- In 2012, spending for long term services and supports, which includes HCBS, was $219.9 billion (9.3 percent of all U.S. personal health care spending)
- Almost two-thirds was paid by the federal state Medicaid program.
Medicaid Home and Community Based Services Overview - Funding

Federal Medical Assistance Percentage (FMAP) for Medicaid and Multiplier

Accessing Services & Supports in your State

• Find out more about the programs available in your state

• Contact your state’s Medicaid office - [Healthcare.gov](#)
• NSCIA Knowledge Book – [State and Local Resources](#)
• NASUAD [State Medicaid Integration Tracker (HCBS, MLTSS …)](#)
• [Healthcare.gov](#) Marketplace Insurance (November 15, 2014)
• Local [Center for Independent Living](#)

• Waiting Lists & Other Issues
  • There are waiting lists for many HCBS waiver programs
  • Talk with a Navigator or counselor about Medicaid expansion or Marketplace insurance in your state and how it could benefit you
Additional HCBS $ and Programs

• **Money Follows the Person** - Medicaid money “follows” the Medicaid beneficiary from a nursing home or other institution to a community-based setting. The ACA extended this program another five years. 44 states and the District of Columbia are running MFP programs. By the end of December 2011, nearly 20,000 people had transitioned to community living.
  • States Not Participating – AK, AZ, FL, NM, UT, WY

• **Community First Choice** - allows states to open eligibility for HCBS to people at higher incomes and to offer additional services. States receive a 6 percentage point increase in FMAP. States may not use the funds for home modifications, room/board, medical supplies, or assistive technology.
  • States Participating or Approved - AR, CA, MD, MN, MT, NY, OR, TX

• **Balancing Incentive Program** - a temporary program that provides qualifying states with increased funds from the federal government for HCBS costs. States that are eligible spent less than 50 percent of Medicaid long-term services funds for fiscal year 2009 on non-institutional care. The program runs from October 1, 2011 through September 30, 2015.
  • States Approved - AR, CT, GA, IL, IN, IA, KY, LA, ME, MD, MS, MO, NV, NH, NJ, NY, OH, TX

• If your state is participating, get involved through stakeholder meetings and councils.
Additional $ and Programs for your State

- **If your state is not participating** – Talk to your state Medicaid office and ask them to apply.

- **HCBS & Community Integration Program Talking Points**
  1. Free Money
  2. HCBS allows people with disabilities to live fuller lives in the community.
  3. Rebalancing, or allowing people with disabilities to live at home instead of in an institution, can be cheaper in the long run for the state.
  4. When people with disabilities are provided the supports they need, like personal attendant services or transportation, they may be more likely to work, pay taxes, and contribute to the community.
  5. There is a growing need for HCBS as states’ residents age.
  6. 15th Anniversary - Olmstead vs. L.C. Supreme Court Decision (June 22, 2014)
  7. 24th Anniversary - Americans with Disabilities Act (July 25, 2014)
Other Medicaid HCBS Issues: Managed Care

- Medicaid Managed Care
  - A state contracts with a managed care organization (MCO) to insure Medicaid recipients.
  - MCOs provide services and supports to consumers through a network of providers for a monthly payment from the state.
  - Alternative to traditional Fee-for-Service, consumers and Medicaid pay providers directly for service

- MCOs direct & administer funds for consumer’s care
  - May lack experience with consumers with disabilities
  - May not prioritize person-centered planning & individual choice
  - May not understand importance of HCBS
  - May cut PCA hours, other supports or services
Other Medicaid HCBS Issues: Managed Care

• Ensuring quality managed care
  
  • If you are already covered by a MCO
    • Can file a grievance, complaint with your insurance provider.
    • Can file an appeal.
    • Work with disability organizations in your state to weigh in on how the program is working. (Community Catalyst has provided a checklist of critical elements for consumers)
    • Contact your state managed long term services and supports ombudsman, local protection and advocacy (P&A) center, or center for independent living.
  
  • If your state is considering adopting managed care
    • Participate in stakeholder meetings and state hearings.
    • Let your elected and agency officials know what matters most to you
  
  • For additional background and resources - United Spinal Association Advocacy Center page on Ensure Quality Medicaid Long-Term Services and Supports and Managed Care
Other Medicaid HCBS Issues: Managed Care

• An Advocate’s Success Story – Finn Bullers
  • In 2013, Kanas began transitioning Medicaid recipients receiving HCBS to managed care
  • Consumers saw a reduction in hours and services
  • 24/7 care to 40 hours a week
  • Self advocacy saved the day and Finn’s services and supports

• Managing Care in Kansas 2014 - 8 minute video tells the story, share it with your networks to learn more
Other Medicaid HCBS Issues: Quality Measures

- Quality Measures (aka data collection and surveys)
  - Can track issue areas of importance, including Medicaid programs provision of:
    - Consumer choice & participant directed services;
    - Satisfaction: Individual Experience with Services and Supports
    - % in employment or meaningful day activity
    - % in independent housing – Consumer choice, housing appropriateness, stability
    - Integrated primary and specialty care
    - Access to timely and appropriate care
  - Quality measures can highlight where a Medicaid program needs work, and can be tools for advocates
National Core Indicators
Aging and Disabilities

- **NCI-AD** - Joint initiative of NASUAD, Human Services Research Institute (HSRI), and NASDDDS
- Survey instrument focused on the performance of publicly-funded aging and disability service systems
- Measures how services impact the quality of life and outcomes of service recipients
- Gathers information directly from service recipients through face-to-face interviews
- Currently in pilot phase in Minnesota, Ohio, and Georgia
- Full expansion to 12 additional states begins June 1, 2015
Other Medicaid HCBS Issues
Stay Tuned

• The Community Integration Act
  • New civil rights legislation
  • Based on the Senate Health, Education, Labor and Pension Committee report: *Separate and Unequal: States Fail to Fulfill the Community Living Promise of the Americans with Disabilities Act*
  • Set to be released around the Anniversary of the Olmstead Decision
  • Ask your congress members to support this bill when it is released
Additional Resources

- HCBS Programs and Rules
  - Centers for Medicaid and Medicare Services: Waivers
  - Friday Morning Collaborative LTSS Webinar Series
  - HCSBAadvocacy.org – Tools to help implement the new HCBS settings rule
  - United Spinal Association Advocacy Center – Advocate for HCBS in Your State

- Olmstead and ADA Anniversary’s
  - ADA.gov – Olmstead: Community Integration for Everyone
  - I Am Olmstead
  - The ADA Legacy Project

- Quality Measures
  - Disability Rights Education & Defense Fund (DREDF), National Senior Citizens Law Center Guide for Advocates: Identifying and Selecting Long-Term Services and Supports Outcome

- Managed Care
  - Consortium for Citizens with Disabilities (CCD) Principles and Recommendations for Transitioning People with Disabilities into Medicaid Managed Care
  - National Disability Leadership Alliance (NDLA) Principles for Providing Coordinated Quality Healthcare in Medicaid Managed Care Programs for those Living with Significant Disabilities
  - National Senior Citizens Law Center
  - DREDF
Get Involved

• Become a **member** of United Spinal Association
  [www.unitedspinal.org](http://www.unitedspinal.org)

• Join United Spinal Association’s **Team Advocacy**
  [www.unitedspinal.org](http://www.unitedspinal.org) – visit our Advocacy Action Center

• Join a **chapter/support group**
  [www.spinalcord.org](http://www.spinalcord.org)

• Become a **policy advisor** at your chapter/support group
  [www.spinalcord.org](http://www.spinalcord.org)

• Become a **grassroots advocate**
  [www.usersfirst.org](http://www.usersfirst.org)
Thank You

Questions?

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