

# Autism Policy Updates

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# Who Are We?

- Nation's largest advocacy group by and for autistic people ourselves
- All-Autistic leadership, plus majority of Board is autistic – including people with significant communication and support needs
- 21 Chapters Nationwide, plus international affiliates and partners



# How Does Self-Advocacy Inform Policy?

- Focus on needs of adults, not just children
- Focus on services and supports that meet pressing needs:
  - Health care
  - Communication
  - Long-term services and supports to enable independent living

# What Demographics Do We Represent?

Our “base” is diverse, and includes:

- People with significant health care needs, such as epilepsy and chronic illness
- People with significant communication needs, including people who type to communicate
- People who require long-term supports to live independently
- Autistic parents of autistic children, including parents of children with very significant needs



# Common Policy-Related Complaints

- Lack of access to quality health care
- Lack of access to transition, employment services
- Problem interactions with police, emergency services, mental health system
- Need for long-term services and supports, especially supports and services to live outside of group home or family home
- Exposure to abusive or counterproductive “therapies” – lack of access to interventions aimed at older children and adults
- Lack of access to communication supports and AAC

# Policy Updates

- New guidance in HCBS Settings Rule
- State Supported Decision-Making Legislation
- Affordable Care Act: Habilitation Services
- Department of Labor Home Care Rule
- Updates on autism safety legislation

# HCBS Settings Rule

- Implements quality controls for services receiving HCBS funding
- Unlike funding for facility-based long-term services, HCBS funding is capped – many wait for years on waiting lists
- Using HCBS funding for institutional services doesn't increase access to institutional services, but *necessarily* means some people can't access more community-based services.
- Many lack meaningful choice to live in non-disability-specific settings



# Goals of Settings Rule

- Require *access* to non-disability-specific settings
- Maximum autonomy, respect, and choice
- Ensure day services focus on the actual interests, schedule, and needs of the person
  - No more “mall therapy” where autistic people must choose from limited options for group-based “recreation”
- Accountability: service providers cannot simply self-certify as “community-based.”



# Current HCBS Developments

- Tennessee plan approved:
  - Conducted extensive site assessments
  - Communicating consistently with broad array of stakeholders (incl. individuals, families)
  - Partnering with DIDD, MCOs
  - Accountability guidelines
- Limits facility-based day services to:
  - Time-limited training OR
  - Based on person-centered plan and aimed at achieving community-living or employment goals

# State Supported Decision-Making Legislation

- Adds a new option to avoid guardianship where possible
- Person with a disability selects a trusted support person to help make decisions, without losing legal capacity
- Passed in Texas; pending in DC (21-385), Delaware (SB 230, House version passed)

# Affordable Care Act

- Essential Health Benefits: coverage of “habilitation services”
- Feb. 2016: Proposed definition of Habilitation Services:

“Health care services that help a person keep, learn or improve skills and functioning for daily living. Examples include therapy for a child who isn’t walking or talking at the expected age. These services may include physical and occupational therapy, speech-language pathology and other services for people with disabilities in a variety of inpatient and/or outpatient settings.”

<https://www.cms.gov/CCIIO/Resources/Regulations-and-Guidance/Downloads/Uniform-Glossary.pdf>

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# Transition to Independence Act

- Voluntary demonstration program
- States rewarded for increasing competitive integrated employment, integrated day services
  - S. 1604, Sponsors: Grassley, Casey, Wyden
  - H.R. 5903, sponsors: Van Hollen, McMorris Rogers, Sessions (R-TX), Langevin (D-RI), Crenshaw (R-FL), Foster (D-IL), Beyer (D-VA)

# Home Care Rule

- Department of Labor now requires overtime + travel pay for almost all HCBS home workers
- Court challenge, based on integration concerns, rejected – SCOTUS denied review in June
- Future focus: ensure states budget for overtime/travel pay when necessary

# Avonte's Law

- S. 2614, recently passed Senate
  - House version pending: H.R. 4919
  - Includes funding for safety training program in addition to tracking devices
  - Still no good evidence base for the most important outcome for tracking devices: preventing injury or death
    - Annual Report will track # of missing persons found but not reduction in missing-persons events
- = Opportunity for research!**

# Questions?