"The Murphy Bill in 2015"

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Protection and Advocacy for Individuals with Mental Illness (PAIMI) Provisions of Concern in H.R. 2646

Curt Decker

Executive Director, NDRN

NATIONAL DISABILITY RIGHTS NETWORK

Protection & Advocacy for Individuals with Disabilities

Protection and Advocacy (P&A) Basics

- Focus of P&A programs is on the person with a disability
- Cross Disability
- Nationwide (all states and territories) & Native American Program in Four Corners region
- Access to People, Places, and Records
- Independent
- Full Range of Remedies
- Strong Investigative and Monitoring Capacity
- Extensive Knowledge of Benefit Systems (Health, Housing, Employment, etc.)

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Authority

“Pursue legal, administrative & other appropriate remedies”

- Range of Issues
- Range of Remedies
- Ability to Respond
- Access Persons, Records, Facilities

Continuum of Remedies

Information and Referrals

Outreach to Un-served and Underserved Populations

Training, including Self – Advocacy Skills

Legal Counsel and Advice

Negotiation and Mediation

Administrative Proceedings

Individual Litigation

Monitoring

Public Policy and Legislative Advocacy

Public Relations

Systemic Litigation and Advocacy

PAIMI Specifics

- PAIMI was enacted in 1986 to prevent abuse and neglect, ensure access to services and supports, and protect the civil and human rights of individuals with mental illness.
- Original focus on those in institutions and within 90 days of discharge.
- Expanded in 2000 to allow PAIMI to serve individuals living in the community, even beyond the original 90 day limit.
- Each PAIMI program has an advisory board made up of people with mental illness, family members, professionals and other informed and active community members.

2014 PAIMI Statistics

- Provided advocacy assistance to 13,936 individual clients.
- Successfully closed 313 systemic advocacy projects and litigation cases that potentially benefits over 27 million individuals.
- Responded to 32,898 requests for information and referral services.
- Participated in 1,903 education and training activities attended by over 82 thousand people, including family members, providers, and people with psychiatric disabilities.
- Investigated 993 suspicious deaths.

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PAIMI Concerns in H.R. 2646

- We appreciate that this year's bill dropped the 85% reduction in PAIMI funding.
- In addition, the prohibition on only doing individual abuse and neglect cases was removed, but replaced with an equally damaging provision.
- Program activity restrictions and other provisions in the bill would eliminate and overly restrict critical PAIMI work.
- None of these proposed changes are based on evidence of the failure of the PAIMI programs to follow the mandates of the PAIMI statute.

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Advocacy for only abuse and neglect

- The first restriction would only allow the PAIMI program to provide advocacy in situations of abuse and neglect.
- This would preclude work involving civil and human rights protection including employment discrimination, denial of educational services, or housing discrimination cases for example.
- There really are no other advocates to step in and do this type of work.

P&A Cannot Be Contrary of Decisions by Doctors or Caregivers

- Another change bars PAIMI from raising concerns with decisions made by doctors, families or guardians.
- This change would have made it impossible for the New York P&A's advocacy to stop unnecessary prostate and cataract surgeries on people with psychiatric disabilities in a Medicaid fraud scheme.
- P&As regularly encounter cases of guardians and family members who can be involved in financial exploitation, abuse, and neglect that would be unaddressed and leave individuals with no recourse.

Help Caregivers Advocate for Health Information

- Another provision would require the PAIMI program to ensure that caregivers have access to protected health information of an individual with a psychiatric disability.
- This restriction is contrary to the intent of the program to provide advocacy for individuals with serious mental illness by making PAIMI provide legal advocacy for the caregiver.
- This creates a situation where this work could violate a lawyer's code of ethics and create a conflict of interest for the lawyer.

Complete Lobbying Prohibition

- Finally, the bill would limit the use of unrestricted funds for lobbying activities.
- An essential part of the P&A legal advocacy role is providing an opportunity for people with disabilities to be heard in the public policy arena.
- Effectuating a positive policy change which benefits tens of thousands of people, is more effective and efficient than conducting individual appeals.
- Limiting the ability of P&As to use their own unrestricted monies to pursue policy outcomes would close a critical avenue for improving the lives of people with mental health disabilities.

The Helping Families in Mental Health Crisis Act and Mental Health Reform Act

- Mental Health Association of Southeastern Pennsylvania Webinar
- Jennifer Mathis | Bazelon Center for Mental Health Law

Judge David L.
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for Mental Health Law

Helping Families in Mental Health Crisis Act: HR 3717 vs. HR 2646

HIPAA (Health Insurance Portability and Accountability Act) Privacy Rights Provisions

- **HR 3717:** Lower privacy standard for individuals with "serious mental illness" (defined as people with a DSM diagnosis that "results in functional impairment of the individual that substantially interferes with or limits one or more major life activities")
- Allows disclosure to such a person's "caregiver" when necessary to "protect the health, safety, or welfare of such individual or the safety of one or more other individuals."
- "Caregiver" is defined as an immediate family member, personal representative, or someone "who assumes primary responsibility for providing a basic need of such individual"

HIPAA (Health Insurance Portability and Accountability Act) Privacy Rights Provisions

- **HR 2646:** Also imposes lower privacy standard for people with "serious mental illness" – disclosure when "necessary to protect the health, safety, or welfare of the individual or general public"
- Adds some qualifications. Disclosure must be "necessary to protect the health, safety, or welfare of the individual or general public."
- The information disclosed must be "beneficial to the treatment of the individual if that individual has a co-occurring acute or chronic medical illness."
- The information disclosed must be "necessary for the continuity of treatment of the medical condition or mental illness of the individual."
- "The absence of such information or treatment will contribute to a worsening prognosis or an acute medical condition."

For more info…List location or contact for specification (or other related documents)

HIPAA (Health Insurance Portability and Accountability Act) Privacy Rights Provisions

- **HR 2646:** "The individual by nature of the severe mental illness has or has had a diminished capacity to fully understand or follow a treatment plan for their medical condition or may become gravely disabled in absence of treatment"
- Permits disclosure of: "diagnoses, treatment plans, appointment scheduling, medications, and medication-related instructions, but not including any personal psychotherapy notes."
- Caregiver: defined the same way as in HR 3717 except for additional requirement that caregiver "can establish a longstanding involvement and is responsible with the individual with a serious mental illness and the health care of the individual; and (E) excludes an individual with a documented history of abuse."
- Individual with "serious mental illness": defined same way as in HR 3717 except that limits coverage of individuals with a developmental disability to those that have a "co-occurring mental illness"

Institutions for Mental Diseases Rule (Medicaid coverage of adults in psychiatric hospitals)

HR 3717: Would establish a new state Medicaid option to provide psychiatric hospital and psychiatric residential treatment services to individuals aged 22-64

- Psychiatric hospital services would cover hospitals or units with an average length of stay of 30 days or less

HR 2646: Would establish the same Medicaid option

- Assistant Secretary for Mental Health and Substance Use Disorders must report on the impact of the change on state funding of psychiatric hospital care and community mental health services
- Assistant Secretary must make recommendations with respect to strategies that can be used to reinvest in community-based mental health services funds equal to the total amount of the state dollars saved on psychiatric hospitals due to the change

Institutions for Mental Diseases Rule (Medicaid coverage of adults in psychiatric hospitals)

Cost neutrality:

- "The amendments made by this section shall not be effective unless the Chief Actuary of the Centers for Medicare & Medicaid Services certifies that the inclusion of qualified inpatient psychiatric hospital services and psychiatric residential treatment facility services . . . furnished to nonelderly adults as medical assistance . . . would not result in any increase in net program spending."

Comparison of HR 3717 and HR 2646 In Their Provisions Regarding SAMHSA, AOT, and Peer Support

Joseph Rogers

Chief Advocacy Officer

Mental Health Association of Southeastern Pennsylvania

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MENTAL HEALTH ASSOCIATION OF SOUTHEASTERN PENNSYLVANIA

SAMHSA Provisions

HR 3717 (2013)

- Created an Assistant Secretary for mental health and substance use disorders to take over responsibilities of SAMHSA
- Terminated all SAMHSA authority over programs not authorized in statute

HR 2646 (2015)

- Creates an Assistant Secretary for mental health and substance use disorders to take over responsibilities of SAMHSA

Continued . . .

SAMHSA Provisions

HR 3717 (2013)

- Cut SAMHSA programs
- Required Congressional approval of programs (including technical assistance centers)
- Created the National Mental Health Policy Laboratory (NMHPL)

HR 2646 (2015)

- Assistant Secretary required to have a degree in medicine or doctorate in psychology with pharmacological training
- Creates the National Mental Health Policy Laboratory (NMPHL)

Continued . . .

SAMHSA Provisions (Cont'd)

HR 3717 (2013)

- Required 50% of grant peer-review groups to have a medical degree or doctoral degree in psychology
- Required 50% of SAMHSA advisory council to have a medical degree or be a licensed mental health professional

HR 2646 (2015)

- National Mental Health Policy Laboratory (NMHPL) (Cont'd):
  - The NMHPL Director must consult with NIMH on hiring decisions;
  - At least 20% of the staff of the NMHPL must have an MD;
  - At least 20% must have a doctoral degree in psychology;
  - At least 20% must be professionals or academics with expertise in substance use disorders;
  - At least 20% must be professionals/ academics with research backgrounds; and
  - At least 20% must be appointed by Congress *Continued …*

SAMHSA Provisions (Cont'd)

HR 2646 (2015)

Both bills support a medical-model system of care!

Neither bill values peer voices in leadership!

- **Requires 50% of grant peer-review groups to have a medical degree, doctoral degree in psychology, or be a licensed mental health professional**
- **Requires 50% of advisory councils to be mental health providers with experience in mental health treatment or research**

Continued . . .

SAMHSA Provisions (Cont'd)

HR 3717 (2013)

- Establishes Interagency Serious Mental Illness Committee to make recommendations to the Assistant Secretary and NIH
  - Committee includes only 1 member in recovery.
    - This individual must currently be in treatment with a mental health professional.
  - Committee includes only 1 family member representative.
  - Remaining membership is largely government administrators and mental health professionals.

HR 2646 (2015)

- Establishes Interagency Serious Mental Illness Committee to make recommendations to the Asst. Sec'y and NIH. Duties now include developing a plan to enhance treatment compliance
  - Committee includes only 1 member in recovery.
    - This individual must currently be in treatment with a MH professional
  - Committee includes only 1 family member.
    - Their family member must have had a suicide attempt or be incarcerated for violence.
  - Committee now includes 1 member that is a CPS.

The Interagency Serious Mental Illness Coordinating Committee largely ignores the voices of people in recovery!

Closing ceremony at Alternatives '85

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Assisted Outpatient Treatment (AOT) Provisions

HR 3717 (2013)

- Center for Mental Health Services block grant funds would be conditional upon a state enacting AOT legislation

HR 2646 (2015)

- Incentivizes states to adopt AOT programs by offering a 2% funding increase.
- To obtain the 2% funding increase, states must have an AOT law in effect.
- Requires a report from states with AOT laws comparing outcomes from people in the program to people who were eligible but did not participate.

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We Oppose Forced Treatment

- **People claim AOT is an evidence-based treatment, but...**
  - **The outcomes have never been compared to the outcomes of a similar group of people receiving proactive engagement services.**
- **AOT is extremely costly.**
  - **This money would be better spent on community-based services, engaged in voluntarily.**
- **Coercive treatment alienates people from seeking help!**

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Peer Support Standards

- **Unlike HR 3717 of 2013, HR 2646 of 2015 includes a section on peer support best practices, training and certification.**
- **The bill's definition of a peer support specialist states:**
  - **The individual must have been in mental health/substance use disorder treatment for at least the preceding 2 years**
  - **The individual must be supervised by a licensed mental health/substance use disorder professional**

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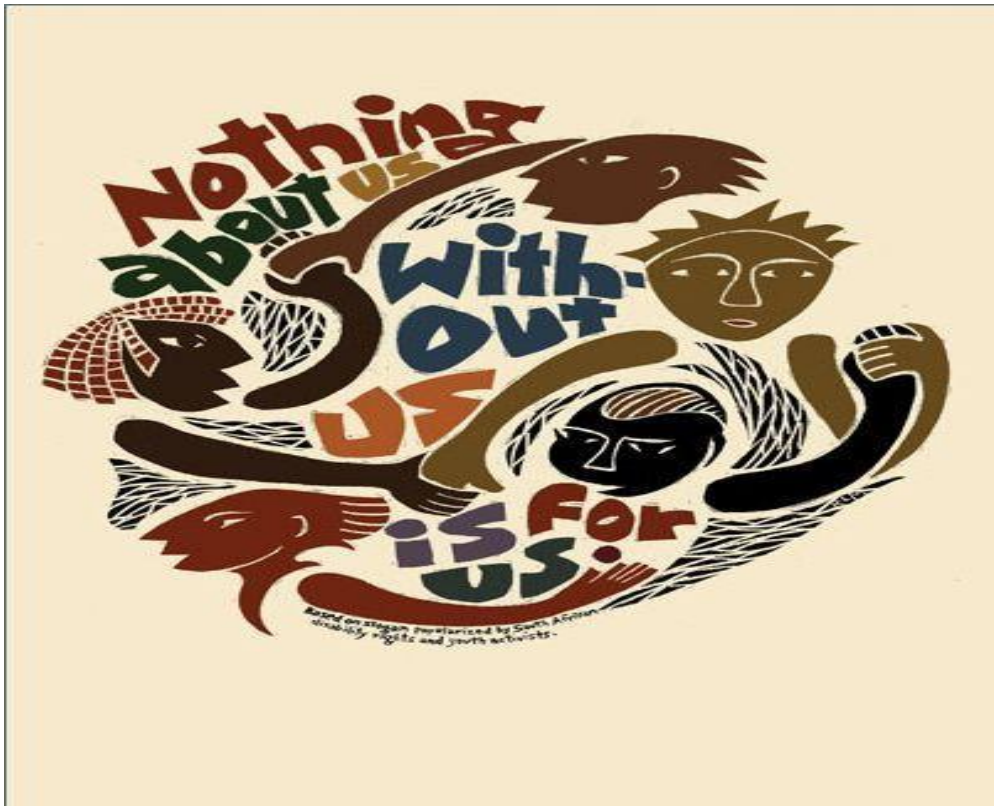
Peer Support Standards (Cont'd)

- **Peer support training and best practice standards should be determined by peer professionals!**
- **Requiring CPSs to be supervised by a licensed clinician creates concerns for peer-run agencies and traditional mental health agencies.**



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Brief Overview of Murphy-Cassidy Bill

- **Presented by Jennifer Mathis of the Bazelon Center for Mental Health Law**

Judge David L.
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for Mental Health Law

Senate bill: Mental Health Reform Act of 2015
S. 1945

- Framed as companion bill to HR 2646
- Similar structure to HR 2646
- Similar grant programs
- Similar provisions about Assistant Secretary for Mental Health and Substance Use Disorders
- No provisions about Protection and Advocacy for Individuals with Mental Illness program

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Senate bill: Mental Health Reform Act of 2015 S. 1945

HIPAA:

- adds factors to be considered as part of determining when disclosure is in a person's "best interests" in situations where person is not present or lacks capacity to consent or object to disclosure:

(1) Timely intervention for treatment of a serious mental or general medical illness"

(2) Safe and stable housing for the individual

(3) Increased daily living skills that are likely to allow the individual to live within the community

(4) An increased capacity of caregivers to support the person to live within the community

Senate bill: Mental Health Reform Act of 2015 S. 1945

HIPAA:

- HHS to develop model training programs for health care providers, lawyers, individuals with psychiatric disabilities and their families concerning HIPAA's application to mental health
- Permit single authorization for disclosure and re-disclosure of electronic health records in integrated care arrangements like health homes, accountable care organizations, and health information exchanges

Senate bill: Mental Health Reform Act of 2015 S. 1945

- Medicaid & psychiatric hospitals:
- Similar provisions to House bill concerning partial repeal of Medicaid IMD rule
- Repeal is for psychiatric hospitals or units with average length of stay of less than 20 days rather than less than 30 days
- Repeal does not cover psychiatric residential treatment facilities as House bill repeal does

Senate bill: Mental Health Reform Act of 2015 S. 1945

- **AOT:** Does not make block grants contingent on states adopting "assisted outpatient treatment" or offer states a 2% enhancement to block grant for states that adopt "assisted outpatient treatment" as House bill does
- But does authorize 2-year extension of the "assisted outpatient treatment" pilot program that passed as part of the Medicare "doctor fix" bill last year.
- **Peer support:** Contains similar but not identical provisions to House bill. Assistant Secretary to do report on best practices and certification standards for peer specialists, & make recommendations.

Judge David L.
BAZELON CENTER
for Mental Health Law

Next Steps for Advocacy

Presented by:
Joseph Rogers
Chief Advocacy Officer
Mental Health Association of Southeastern Pennsylvania

Share your story!

- **Write to or call your senators and representative!**
- **Coordinate a Twitter day of action!**
- **Educate people in your community!**
- **Reach out to the press; write letters to the editor!**

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Campaign for Real Change in Mental Health

http://realmhchange.org

Features:

- Petition
- Blogs
- Talking points
- Compilation of statements
- Check back for frequently updated content

"The Campaign recognizes that we don't have to sacrifice people's civil rights to create an effective mental health system. The Campaign also believes that to enact any 'mental health reform' that does not take a comprehensive public health approach is a missed opportunity."

CAMPAIGN FOR REAL CHANGE IN MENTAL HEALTH POLICY

Questions and Discussion