



## **ALTERNATIVES 2018 PRE-CONFERENCE POLICY PRIORITIES FOR HILL DAY**

### **PRIORITY 1: Ensure significant peer participation in the development of national and state mental health policies.**

**SIGNIFICANCE OF THE PRIORITY:** When making decisions on policy and practices at the federal or state level, it is essential to include the voices of those who truly have an informed perspective on issues concerning mental health and substance use disorders. The decisions to be made by governing entities will directly impact their course of Recovery and their fundamental human rights.

#### **RECOMMENDATIONS:**

1. Create a Substance Abuse and Mental Health Services Administration (SAMHSA) committee of persons with lived mental health and/or substance use experience (also known as consumers or peers) that would fully participate in the creation of all SAMHSA initiatives. The committee members would be responsible for all appointments to the committee.
2. Ensure that a majority of the members of all state planning councils consist of persons with lived mental health and/or substance use experience, and that they meaningfully participate in the allocation of state Mental Health and Substance Use Block Grant funds.
3. Further define Code of Federal Regulations 42, Section 431.12, by stating that at least two representatives from the committee be persons with lived mental health experience.
4. Expand federal funding of the national consumer-run technical assistance centers to cover five regional centers, each responsible for organizing advocacy in a region of the country. The major responsibility of these technical assistance centers would be the nurturing and sustenance of statewide consumer-run advocacy organizations.
5. Expand federal funding of statewide consumer-run organizations to cover one such organization per state, ensuring that each state have a consumer/survivor voice in the development of state policies, as recommended by The President's New Freedom Commission on Mental Health.

#### **TALKING POINTS:**

1. **Create a Substance Abuse and Mental Health Services Administration (SAMHSA) committee of persons with lived mental health and/or substance use experience (also known as consumers or peers) that would fully participate in the creation of all SAMHSA initiatives. The committee members would be responsible for all appointments to the committee.**
  - a. SAMHSA used to have a Center for Mental Health Services (CMHS) Consumer Advisory Committee, but it has not met in a long time. Currently, the committee on long-term mental health issues includes only one person with lived experience. The involvement of consumers in SAMHSA policy would be in accordance with the recommendation of the report of the New Freedom Commission on Mental Health, which emphasized the importance of "involving consumers and families fully in orienting the mental health system toward recovery."

- b. Following is a direct quote from The President’s New Freedom Commission’s final report:  
“Successfully transforming the mental health service delivery system rests on two principles:
  - i. “Services and treatments must be consumer and family centered, geared to give consumers real and meaningful choices about treatment options and providers—not oriented to the requirements of bureaucracies.
  - ii. “Care must focus on increasing consumers’ ability to successfully cope with life’s challenges, on facilitating recovery, and on building resilience, not just on managing symptoms.”

**Reference:** The President’s New Freedom Commission’s final report, *Achieving the Promise: Transforming Mental Health Care in America*. Page 5, 2003. <https://tinyurl.com/ybdnyzrm>

**2. Ensure that a majority of the members of all state planning councils consist of persons with lived mental health and/or substance use experience, and that they meaningfully participate in the allocation of state Mental Health and Substance Use Block Grant funds.**

- a. Presently, the block grant allocation to the states is to be determined by collaboration between the departments of mental health and the State Planning Councils. There is a need for greater oversight by the Mental Health Block Grant division of SAMHSA to ensure that there is adequate representation by consumers and that the voices of those consumers on the State Planning Council are actually heard and affect how the block grant is spent. The New Hampshire State Planning Council is a good example of significant consumer involvement due to strong peer leadership and advocacy. As a result, a significant percentage of their Block Grant resources support peer-run activities.

**References:**

- New Hampshire Department of Health and Human Services, Office of Family and Consumer Affairs <https://www.dhhs.nh.gov/dcbcs/bbh/ocfa.htm>
- How State Mental Health Agencies Use the Community Mental Health Services Block Grant to Improve Care and Transform Systems <https://tinyurl.com/yb3d2zjh>

**3. To further define Code of Federal Regulations 42, Section 431.12, by stating that at least two representatives from the committee be persons with lived mental health experience.**

- a. Although there is a federal policy that states that recipients of Medicaid must be on the committee, these Councils rarely include mental health peers, and rarely have influence on state Medicaid policy decisions. Massachusetts has such a committee that advises its Medicaid managed care company. Since a majority of public mental health services are funded by Medicaid, it is imperative that mental health consumers participate in design of benefits, quality improvement, policies and practices.

**Reference:**

- Section of the Code of Federal Regulations 42, Section 431.12 <https://tinyurl.com/yct3avxu>

**4. Expand federal funding of the national consumer-run technical assistance centers to cover five regional centers, each responsible for organizing advocacy in a region of the country. The major responsibility of these technical assistance centers would be the nurturing and sustenance of statewide consumer-run advocacy organizations.**

- a. There have been three consumer-run Technical Assistance Centers (TAC) for 20 years and 2 dating from 1992. These TACs provide technical assistance to the statewide consumer-run organizations, as well as for the development of peer-run alternatives such as peer-run crisis respites and warmlines. These need expansion to be able to meet the needs of all 50 states plus the District of Columbia and territories. Furthermore, there is a need to refund the annual

Alternatives Conferences, which are organized by and for individuals with lived experience of a mental health condition.

**References:**

- The National Consumer and Consumer Supporter Technical Assistance Centers <https://tinyurl.com/yd2udvpt>
- Now Is The Time Technical Assistance Center <https://www.samhsa.gov/nitt-ta>
- 2018 Alternatives Conference <https://www.alternatives-conference.org>

**5. Expand federal funding of statewide consumer-run organizations to provide necessary support for one such organization per state, ensuring that each state have a consumer/survivor voice in the development of state policies, as recommended in the report of the President’s New Freedom Commission on Mental Health.**

- a. There still are 23 states that lack statewide consumer-run organizations that can bring the voices of consumers to the decision makers. SAMHSA administers grants to assist these states in the sustainability of existing statewide organizations but there also is a need for newly forming groups to be funded.

**References:**

- National Association of State Mental Health Program Directors, Mental Health Links, including to each of the state programs <https://www.nasmhpd.org/content/mental-health-links>
- The President’s New Freedom Commission final report, *Achieving the Promise: Transforming Mental Health Care in America*. 2003. <https://govinfo.library.unt.edu/mentalhealthcommission/reports/FinalReport/downloads/downloads.html>

**APPENDIX**

- The Report of the President’s New Freedom Commission on Mental Health<sup>i</sup>, 2003, SAMHSA, Rockville, MD, states: “Goal 2: Mental Health Care is Consumer and Family Driven—**Recommendation 2.2: Involve consumers and families fully in orienting the mental health system toward recovery.**”
- Grantees use the block grant programs for prevention, treatment, recovery support, and other services to supplement Medicaid, Medicare, and private insurance services.
- Reference: “Best Practices for State Behavioral Health Planning Councils: The Road to Planning Council Integration,” SAMHSA (2014). <https://tinyurl.com/y8nsjlzu>

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**PRIORITY 2: Develop and sustain alternatives to involuntary treatment by increasing the availability of peer-run crisis respites and other peer-run crisis supports.**

**SIGNIFICANCE OF THE PRIORITY:** Peer-run crisis respites provide a range of supports to individuals who may be experiencing a mental health crisis. These peer-run services offer an innovative alternative and/or complementary service to traditional emergency room or inpatient hospital care.

## RECOMMENDATIONS:

1. Ensure that the Substance Use and Mental Health Services Administration (SAMHSA) sets aside 20% of Mental Health Block Grant funding to support the expansion of peer-run crisis respites and other peer-run crisis supports.
2. Advocate for increased technical assistance to promote integrated and collaborative approaches to funding peer-run services.
3. Support funding for rigorous research on the impact of peer-run crisis supports by funding five peer-run crisis respite pilots located in different regions of the U.S., to further document the efficacy of these services.
4. Support successful peer integration into the workforce by strongly advocating for the creation of a national Peer Workforce Center of Excellence<sup>1</sup> (or a similar program) to develop training and technical assistance for peer support workers and agencies that employ them.
5. Fully implement the CMS 2014 HCBS Regulations for people with mental health needs, including person-centered planning, self-direction, and full access to the broader community.
6. Support passage of the Disability Integration Act (S910/HR2472).

## TALKING POINTS:

1. **Ensure that the Substance Use and Mental Health Services Administration (SAMHSA) sets aside 20% of Mental Health Block Grant funding to support the expansion of peer-run crisis respites and other peer-run crisis supports.**
2. **Advocate for increased technical assistance to promote integrated and collaborative approaches to funding peer-run services.**
  - a. Unlike traditional hospital inpatient settings available to individuals in need of immediate attention for psychiatric symptoms, crisis services include an array of supports that are designed to reach individuals in their communities.
  - b. Peer-run crisis supports include telephone “hotlines” or “warm lines,” mobile outreach, and short-term crisis respite centers.
  - c. Such alternatives to hospitalization have had a positive impact on quality of life domains such as wellness and community inclusion and provide significant cost savings (SAMHSA, 2015).
  - d. Despite emerging evidence to support the positive impact of peer-run crisis respites and other peer-run crisis supports, coverage for these services has varied across different payer types (Medicaid, Medicare, Managed Care, etc.) and is inadequate to meet the growing demand for these services (NEC,2018).

Limited availability of treatment options eliminates individual choice and self-determination (which undermines recovery).

***To ensure ongoing viability and expansion, peer-run services must be able to leverage funds from all available sources (federal, state, local, and private).***

***Ongoing technical assistance is needed to ensure that peer-run programs are able to successfully engage in collaborative funding.***

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<sup>1</sup> Note: Bills such as H.R.2046 Peer-Support Specialist Act of 2017—to provide for a report on best practices for peer-support specialist programs, to authorize grants for behavioral health paraprofessional training and education—might also address this need.

- Crisis Services: Effectiveness, Cost-Effectiveness, and Funding Strategies, SAMHSA. <https://store.samhsa.gov/shin/content/SMA14-4848/SMA14-4848.pdf>
- National Empowerment Center: Evidence for peer-run crisis alternatives <https://power2u.org/evidence-for-peer-run-crisis-alternatives/>
- Peer Support Wellness Respite Centers, SAMHSA-HRSA, Center for Integrated Health Solutions <https://www.integration.samhsa.gov/images/res/PDF,%20PSWRC.pdf>

**3. Support funding for rigorous research on the impact of peer-run crisis supports by funding five peer-run crisis respite pilots located in different regions of the U.S., to further document the efficacy of these supports.**

- a) There is a growing body of evidence that suggests peer-run crisis alternatives can have positive impacts on a range of health and wellness measures.<sup>2</sup>
- b) While the availability and demand for these services continues to grow, few experimental trials of their effectiveness have been conducted.
- c) Evaluating the full impact of peer-run crisis supports as an evidence-based practice has been hindered by varying definitions of peer-run crisis supports, a lack of established measures; variations in training and certification of the workforce, unstructured service and intervention models, a lack of established outcome measures, and a uniform model of peer-delivered services.

***A coordinated research agenda is needed to continue developing the evidence for peer-delivered services.***

**4. Support successful peer integration into the workforce by strongly advocating for funding for a Peer Workforce Center of Excellence (or a similar model) to provide training and technical assistance for peer support workers and agencies that employ them.**

- a. A unique feature of peer-run crisis supports is their employment of individuals with behavioral health conditions (peer support workers), who use their experiences as service recipients to support individuals experiencing a behavioral health crisis.
- b. Peer Support Workers have received specialized training—e.g., Intentional Peer Support, Trauma-informed Peer Support, Wellness Recovery Action Planning (WRAP)—that, combined with their lived experience of a mental health condition and of mental health services, enables them to successfully engage individuals experiencing a behavioral health crisis and produce favorable health outcomes that traditional service providers often cannot.
- c. In 39 states, peer support services are now reimbursable through Medicaid, which has created unprecedented opportunities for the expansion of this workforce.
- d. Despite the recent expansion of the peer workforce, peer supporters report numerous barriers to successfully entering the workforce, such as a lack of clarity about the role/value of peer supporters in the workplace; limited opportunities for ongoing training and professional development, i.e., a limited career ladder; low wages; and discrimination in the workplace.

***Federal funding is needed to address the needs of this workforce and identify best practices for integration into the behavioral health service system.***

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<sup>2</sup> For more information, see Agar-Jacomb & Read, 2009; Burns-Lynch & Salzer, 2001; Greenfield, Stoneking, Humphreys, Sundby, Bond 2008; Bond, 2008; Kiesler Kiesler, 1982; Landers & Zhou 2009; Lloyd 1982; Landers, & Zhou, 2009; LloydEvans, Slade, Jagielska, Johnson, 2009; Mendel & Rapport, 1969; Mosher, 1999; Stein & Test, 1980; Toprac, Sherman, Holzer, et al., 1996; Whittle, 1992).

**References:**

- Peer Support for the Hardly Reached: A Systematic Review. Rebecca Sokol BS, and Edwin Fisher PhD. <https://ajph.aphapublications.org/doi/abs/10.2105/AJPH.2016.303180>
- “Peer workers’ perceptions and experiences of barriers to implementation of peer worker roles in mental health services: A literature review. “Vandewalle J, Debyser B, Beeckman D, Vandecasteele T, Van Hecke A, Verhaeghe S. <https://www.ncbi.nlm.nih.gov/pubmed/27297384>
- “39 States Cover Peer Support Services for Behavioral Health” <https://tinyurl.com/ybuag9hm>

**5. Fully implement the CMS 2014 HCBS Regulations for people with mental health needs, including person-centered planning, self-direction, and full access to the broader community.**

- a. The 2014 final Home and Community-Based Services (HCBS) regulations established new requirements for several Medicaid authorities under which states may provide home and community-based long-term services and supports. The regulations enhance the quality of HCBS and provide additional protections to individuals that receive services under these Medicaid authorities.
- b. Revisions/clarifications of eligible home and community-based settings will maximize opportunities for participants in a Home and Community Based Services programs to have access to the benefits of community living and to receive services in the most integrated setting. The intention of the law was for Medicaid HCBS to provide alternatives to services provided in institutions.

**References:**

- Home and Community Based Services Final Regulations – Home page with several links <https://www.medicaid.gov/medicaid/hcbs/guidance/hcbs-final-regulation/index.html>
- Home and Community Based Services Final Rule 2014—Fact Sheet <https://www.medicaid.gov/medicaid/hcbs/downloads/final-rule-fact-sheet.pdf>
- CMS Gives States Extra Three Years to Comply with HCBS Reform <https://tinyurl.com/y9s68qrb>
- How States Can Prevent Evictions When Implementing Federal HCBS Regulations <https://tinyurl.com/yawjjhtl>

**6. Support passage of the Disability Integration Act (S910/HR2472).**

- a. Over 25 years after the signing of the Americans with Disabilities Act (ADA), institutionalization seriously interferes with the liberty of people with disabilities and seniors. A Senate Committee report documented the failure of States to secure and protect the liberty of people with disabilities and seniors by refusing to provide community-based services.
- b. That report recommended that Congress strengthen the ADA integration mandate to clarify that States and private insurers cannot interfere with every American’s right to liberty by failing to provide Long Term Services and Supports (LTSS) in the community.

**References:**

- Disability Integration Act Fact Sheet <http://www.disabilityintegrationact.org/fact-sheet/>
- Senate HELP Committee report: “Separate and Unequal: States Fail to Fulfill the Community Living Promise of the Americans with Disabilities Act” <https://tinyurl.com/y9mshlg2>



## **PRIORITY 3: Protect the human rights of persons labeled with mental health conditions.<sup>3</sup>**

**SIGNIFICANCE OF THE PRIORITY: Individuals cannot even begin the Recovery process while in the midst of suffering significant human rights violations.**

### **RECOMMENDATIONS:**

1. Expand funding of the Protection and Advocacy for Individuals with Mental Illness (PAIMI) program to ensure due process and other protections under the Constitution.
2. Work to end involuntary treatment and coercive treatments, such as physical and chemical restraints, which restrict freedom and violate the principles of self-determination.
3. Strongly advocate that the U.S. Congress ensure that the Justice Department enforce protections such as guaranteed under the Americans with Disabilities Act (ADA) and the *Olmstead* decision.
4. Oppose repeal of the IMD (Institutions for Mental Diseases) exclusion.

### **TALKING POINTS:**

- 1. Expand funding of the Protection and Advocacy for Individuals with Mental Illness (PAIMI) program to ensure due process and other protections under the Constitution.**
  - A. PAIMI was established in 1986, originally to investigate abuse and neglect and rights violations affecting people with mental health conditions in institutions.
  - B. PAIMI was expanded in 2000 to cover both people in institutions and in the community, including in their own homes. This was a result of the 1999 *Olmstead* decision, which upheld the community integration mandate of the Americans with Disabilities Act.
  - C. While the population of people whom PAIMI can serve has expanded, the funding has remained fairly level.
  - D. In 2017, the National Disabilities Rights Network (NDRN) recommended a funding level of \$40 million for 2018; in 2016, it was \$36 million.

**Reference:** “Protection and Advocacy for Individuals with Mental Illness (PAIMI) Fiscal Year 2018 Appropriations Recommendation—\$40 Million”: <https://tinyurl.com/yblwn5up>

- 2. Work to end involuntary treatment and coercive treatments, such as physical and chemical restraints, which restrict freedom and violate the principles of self-determination.**
  - A. Forced treatment a serious rights violation.
  - B. Forced treatment is counterproductive.
    - a. Fear of being deprived of autonomy discourages people from seeking care.
    - b. Coercion undermines therapeutic relationships and long-term treatment.
    - c. The reliance on forced treatment may confirm false stereotypes about people with mental health conditions being inherently dangerous.
    - d. Forced treatment is traumatic and humiliating, often exacerbating a person’s mental health condition.
  - C. Pennsylvania demonstrated that the use of seclusion and restraints could be reduced and even eliminated.

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<sup>3</sup> Much of the language in this fact sheet was copied verbatim from the references listed.

- a. Pennsylvania state hospitals participated in an aggressive statewide program to significantly reduce the use of seclusion and restraints, with impressive results:
  - i. According to Steven Karp, DO, former Chief Psychiatric Officer of the PA Department of Public Welfare, seclusion hours "...dropped from more than 5,000 in February 1993 to just over 4 in February 2003. During this same period, the number of mechanical restraint hours dropped from almost 11,000 to slightly more than 90. Two state hospitals in Pennsylvania have not used restraints, and two others have not used seclusion, in more than two years."
  - ii. Staff injuries did not increase during this period as a result of decreased use of seclusion and restraints.
  - iii. The clinical literature on mental health treatment frequently refers to this statewide success story as evidence that a safe environment can be attained for psychiatric patients without resorting to force.
  - iv. The state hospitals' change in delivery of care was an extraordinary accomplishment which was acknowledged in October 2000, when Pennsylvania's Seclusion and Restraint Reduction Initiative received the prestigious Harvard University Innovations in American Government Award.

**References:**

- Bazelon Center for Mental Health Law Forced Treatment Overview <http://www.bazelon.org/our-work/mental-health-systems/forced-treatment/>
- Involuntary Outpatient Commitment Myths and Facts (National Coalition for Mental Health Recovery) <https://tinyurl.com/yakjxl99>
- Hartford Courant Deadly Restraint Investigation Data Base <https://tinyurl.com/7e556>
- "Changing the Culture of Seclusion and Restraint." PA PSRS Patient Saf Advis 2005 Mar;2(1):22-6. <https://tinyurl.com/yc75beu4>

**3. Strongly advocate that the U.S. Congress ensure that the Justice Department enforce protections such as guaranteed under the Americans with Disabilities Act (ADA) and the *Olmstead* decision.**

- A. "The ADA is a civil rights law that prohibits discrimination against individuals with disabilities in all areas of public life, including jobs, schools, transportation, and all public and private places that are open to the general public. The purpose of the law is to make sure that people with disabilities have the same rights and opportunities as everyone else."
- B. "On June 22, 1999, the United States Supreme Court held in *Olmstead v. L.C.* that unjustified segregation of persons with disabilities constitutes discrimination in violation of title II of the Americans with Disabilities Act."
- C. "In 2009, the Civil Rights Division launched an aggressive effort to enforce the Supreme Court's decision in *Olmstead v. L.C.*, a [1999] ruling that requires states to eliminate unnecessary segregation of persons with disabilities and to ensure that persons with disabilities receive services in the most integrated setting appropriate to their needs."

**References:**

- "What is the Americans with Disabilities Act?" <https://adata.org/learn-about-ada>
- "Olmstead: Community Integration for Everyone" <https://www.ada.gov/olmstead/>
- National Mental Health Consumers' Self-Help Clearinghouse amici brief in *Olmstead v. L.C.* <https://tinyurl.com/y7fxprct>
- H.R. 6035: Community Integration Act of 2016 <https://www.congress.gov/bill/114th-congress/house-bill/6035>

**4. Oppose repeal of the IMD (Institutions for Mental Diseases) exclusion.**

- A. The IMD exclusion prohibits Medicaid coverage of state and private psychiatric hospitals with more than 16 beds, except under strict capitated waivers (such as Vermont and Massachusetts have). Eliminating the IMD exclusion would violate the *Olmstead* decision, which mandates treatment in the least restrictive environment.

**References:**

- Bazelon Center for Mental Health Law letter opposing repeal of the IMD exclusion, April 19, 2018  
<https://tinyurl.com/y9brbuj8>
  - “Medicaid’s Institutions of Mental Diseases (IMD) Exclusion Rule: A Policy Debate”  
[http://www.scattergoodfoundation.org/sites/default/files/IMD\\_Exclusion\\_Rule\\_Debate\\_053118.pdf](http://www.scattergoodfoundation.org/sites/default/files/IMD_Exclusion_Rule_Debate_053118.pdf)
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