

### **Policy and Advocacy Essentials: A Guide for Providers**

15<sup>th</sup> Annual Recovery and Rehabilitation Academy November 15, 2024

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## Today's Agenda

- Introductions
- Who is The Alliance for Rights and Recovery (formerly NYAPRS)?
- Approaches and Impact of Advocacy
- Why Advocacy is Important for People using Services
- Why Advocacy is Important for Service Providers
- An Example of Successful Program Advocacy
- Questions and Answers

## **Our Mission**



The Alliance for Rights and Recovery is a state and national change agent dedicated to improving services, public policies and social conditions for people with mental health, substance use and trauma-related challenges, by promoting health, wellness and recovery, with full community inclusion, so that all may achieve maximum potential in communities of choice.

### Alliance Board and Staff Team

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### The Alliance Overview

- State and National Grassroots Human Rights Advocacy Coalition
- NYS based Member Association
- State and National Advocate for Rights, Recovery, Equity and Inclusion
- State and National Training and Technical Assistance Center
- Peer Service Innovations and Technical Assistance
- State and National Conferences and Webinars





# We came to raise the bar











**Rights, Choice and Self-Determination** 

# We came to raise the bar



#### **Social and Racial Justice**

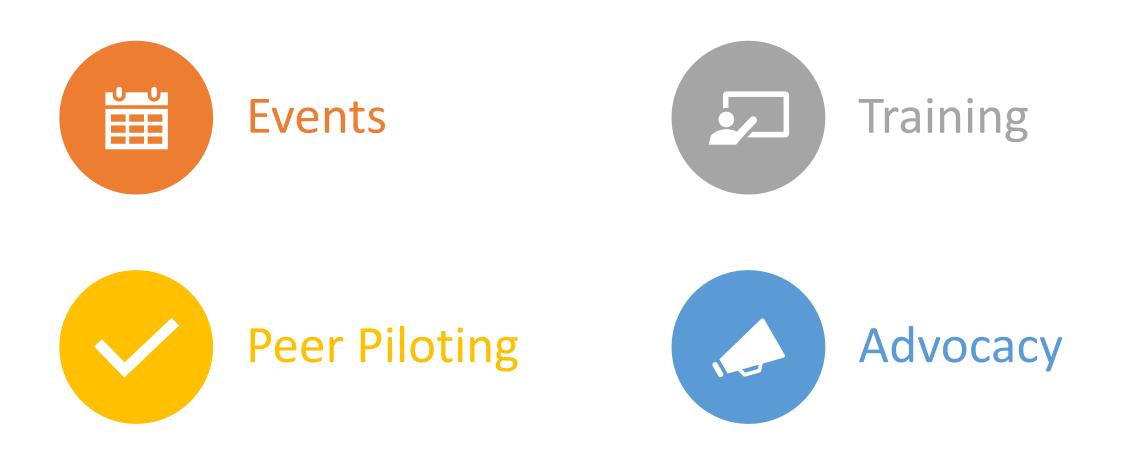


**Social Determinants of Health** 

The Alliance (formerly NYAPRS) Policy Priorities 1992-Present

- Expansion of availability, access and funding for Community Services
- Recovery is the Expectation for All
- Rights, Choice and Self-Determination should drive policy Recovery, Hope and Dignity
- Opposing Coercion and Abuse
- Promoting Social and Racial Justice
- Pathways to Recovery: Peer Support, Rehabilitation
- Community Inclusion: Housing, Employment, Transportation, Social Networks

### How the Alliance Achieves Our Goals



### Peer Innovation, Recovery Training and Technical Assistance

- Peer Service Innovations: State Peer Bridger Pilots, Peer Core Navigator Project, National TA for Peer Agencies in other states, Academy of Peer Services, SAMHSA SPARK initiative, National Council Peer Services and CCBHCs TA
- Recovery and Rehabilitation Centered Services:
  Collective, New York Psychiatric Rehabilitation Training
  Academy, Managed Care Initiatives

### Self Advocacy

### At Our Heart: Advocacy

### **Peer Advocacy**

### Systems Advocacy



## Why Advocate?









### Judi Chamberlin

 "People are still being punished for being in pain, for feeling their pain and for trying to speak their pain; and that's why there's such a ginormus need for alternative crisis facilities that we need to develop. Because yeah, it is hard to be around somebody who is not sleeping, or crying all the time, or screaming or tearing at their flesh, or whatever. What's so important is to try to connect people with that this is real and this is what they are feeling."



# Lois Curtis vs Olmstead

- Lois Curtis, a woman who was diagnosed with a mental health condition, had been kept in a locked institution for years despite clinicians determining she could receive care in her home
- After years of neglect, Curtis and another woman, Elaine Wilson, sued the state of Georgia.
- The case went to the Supreme Court, who decided it was a violation of the Americans with Disabilities Act to keep people in institutions when they could reasonably live in the community



"I hope they live long lives and have their own place. I hope they make money. I hope they learn every day. I hope they meet new people, celebrate their birthdays, write letters, clean up, go to friends' houses and drink coffee. I hope they have a good breakfast every day, call people on the phone, feel safe."

- Lois Curtis (on her hopes for others like her)





### How we Accomplish our Goals



Regular Meetings and Advocacy with State Legislators and Leadership



Connection with state agencies supervising services



Getting representation at every important table where decisions are made



Regional meetings with stakeholders to determine needs and priorities

People who use services Providers of services Local Advocates Local government representatives



# A's Law isn't answer for mentally

when / base at A the menstate and dra's Law," are being jeorge Pataki, a A Assembly fon Silver, a

ures came on the e death of Kendra , who was pushed under .ork City subway last , y by a mental patient, w Goldstein. EDITORIAL Majority Leader Joseph L Bruno should step up to the plate and back his colleague's plan to the

Kendra's Law proposes involuntary outpatient commitment, which basically provides courtordered outpatient treatment for mental patients. While this "tough on criminals" -- mentally ill or otherwiselegication place well with the second seco

nals" — mentally ill or otherwise — legislation plays well with the public on first blush, it is really a weak measure that does not deal with the real flaws in New York state's mental-health system: A better proposal has been put forward by state Sen. Thomas

Libous, and we believe Senate

would allocate \$3 million for a pilot program that would provide individualized residential care and support services for "at risk" individuals with major mental illnesses. It would also consumes montal

It would also encourage mental health consumers to prepare an advance directive and appoint a health care proxy for times of difficulty.

runo The problems with Kendra's ad Law are many. he It would force treatment and

It would force treatment and medication on people with no histories of violence; it could force mental health professionals to lose the confidence of their clients by becoming agents of the e. court; it contains no money for the extra duties required of eourds, county and state officials, police and emergency personnel. For some 30 years the state has 1 been de institutional-zing the

been de insultational zing the mental health system. But over time, and especially during the Pathai administration, many mentally ill people have those who need help. New York state can do and we believe the prop-Sen. Libous is a step in.

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#### **Alliance State Policy Advocacy**

- Legislator Meetings and Budget Advocacy
- Testimony before legislative bodies
- Albany Rallies and Yearly Legislative Day
- Media Work





### **News Conferences**



The Alliance (formerly NYAPRS) Policy Achievements and Priorities 1992-Present **Criminal Justice Reform**: solitary confinement, first responders, re-entry policy

**Medicaid** Redesign, 1115 Waiver, CORE, IMD Exclusion

Racial Equity And Justice, Anti-racism Initiatives

#### **Psychiatric Advance Directives**

# Why Advocacy is Important for People Receiving Services

- People with mental health challenges often experience stigma, shame, and discrimination due to their challenges
- The mental health system also subjects people to a loss of control, rights, and choice
- People are often identified with their mental health challenge, rather than the other valuable roles they have, including as a family member, spouse, employee, homeowner, etc

# Why Advocacy is Important for People Receiving Services

- Engaging in advocacy allows people to regain a sense of control in their lives and use their skills to make meaningful changes in their communities
- What do people gain from participating in advocacy?
  - Empowerment and Personal Growth
  - Reduced stigma and increased awareness
  - The ability to shape policies and programs to fit their desires and needs
  - Connection with a supportive community
  - Becoming a symbol of hope and change

# Empowerment and Personal Growth

- **Building Confidence**: Advocacy allows people with mental health challenges to share their stories, turning lived experiences into valuable resources that can inspire others and foster personal empowerment.
- **Skill Development**: Participation often involves developing public speaking, networking, and leadership skills, which can increase self-esteem and promote a sense of achievement.
- **Purpose and Motivation**: Many people utilizing services find purpose in advocating for causes that directly impact their lives, providing them with a meaningful goal and helping them focus on their personal growth





# Reducing Stigma and Increasing Awareness

- Challenging Stereotypes: By openly discussing their experiences, mental health advocates dispel myths and challenge harmful stereotypes, demonstrating that mental health challenges can affect anyone, and recovery is truly possible
- Humanizing Mental Health Issues: Personal stories and firsthand accounts help the public see beyond labels, understanding people with mental health challenges as individuals rather than identifying them as their "conditions."
- **Promoting Social Acceptance**: Advocacy helps create a climate of acceptance, where mental health challenges are seen as part of human diversity rather than as stigmatizing flaws.

Nothing About Us Without Us: Shaping Policies and Practices

- Influencing Legislation: People experiencing mental health challenges who advocate can have a direct impact on policies, encouraging lawmakers to consider the real-world effects of mental health laws on the people
- Improving Mental Health Services: By sharing our insights into what works (and what doesn't) in mental health care, advocates help shape services that better meet our needs and ensure decisions aren't made about us without our input
- Promoting Access to Resources: Mental health advocates often push for increased funding, better insurance coverage, and expanded access to care, which can lead to tangible improvements for people using services now and in the future



# Nothing About Us Without Us: Shaping Policies and Practices



#### Creating Accountability: By

speaking out, people with lived experience hold mental health providers, policymakers, and insurance companies accountable for the quality and accessibility of services they provide.



#### **Promoting Person-Centered**

**Care**: Advocacy from people with mental health challenges pushes for systems that respect our rights, preferences, and individual needs. 3

Advocating for Research: The voices of people with lived experiences can drive demand for more mental health research, focusing on areas that we identify as critical to improving services and care options.

# Public Education and Increased Awareness

- Educating the Public: Advocates inform others about the complexities of mental health issues, helping the public understand various challenges, available services, and the barriers people face.
- Increasing Early Intervention: Raising awareness about mental health issues encourages others to seek help early, potentially preventing more major challenges in the future.
- **Highlighting Diversity in Mental Health**: Advocates can share diverse perspectives, illustrating how mental health challenges affect people differently based on culture, background, and socioeconomic factors

## Creating Hope and Inspiration for Others

- **Inspiring Others**: When people with mental health challenges advocate, they inspire others facing similar challenges, showing that recovery and improvement are possible and worth fighting for.
- **Creating Lasting Change**: Our participation contributes to long-term improvements in the mental health care landscape, leaving a legacy that can help future generations.
- Fostering Hope: By working towards positive change, advocates foster a culture of hope, where mental health challenges are addressed proactively rather than reactively and all understand recovery is not just possible, but the goal!



## Why Advocacy is Important for Providers

#### Improving the lives of those you serve

• Providers have a much better understanding of what the folks they serve need most as well as the current gaps in service provision

#### • FUNDING!!!

 Advocacy for providers often directly leads to increased funding for services and workforce compensation

#### Improving Access to Care

 Increasing access to services by expanding offered supports, reducing barriers to care, and widening the number of people served all require advocacy from both people receiving services and providers

Why Advocacy is Important f∩r Providers

- Enhancing Services to make them more effective
- Improving working conditions and support for providers
- Creating a more Culturally Competent System for people using services
- Strengthening Community Support Systems
  - Often advocacy from program providers can involve pushing for services they do not offer themselves, but know would better support their communities and make their day to day jobs easier

## What You Can Do to Start Advocating

Educate Yourself

Organize like minded people through conferences, local forums/town halls, training, and the creation of coalitions

1 - Control

Develop relationships with legislators

Use your skills!

Everyone brings different talents which are useful for advocacy



Connect with National Organizations like the Alliance for Rights and Recovery



## <sup>v</sup> 3rief Guide for Legislative Meetings

#### • What to Expect

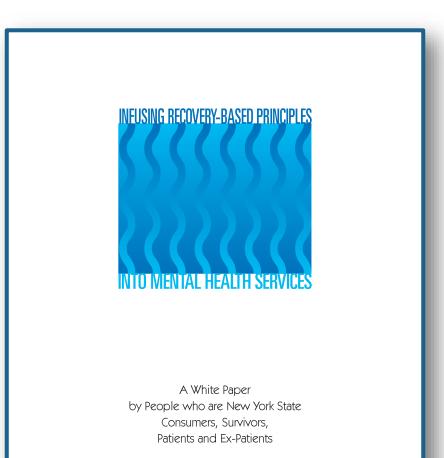
- Brief meetings, 30 minutes at most
- Do not feel discouraged if your meeting is with an elected official's staff, not the elected themselves
- Legislative Staff are the ones who gather information and help the legislators make decisions on how to vote on issues. Getting their staff on our side is critical!

#### • Roles at Legislative Meeting

- Introduction: This person introduces the group as part of the Alliance Legislative Day.
- **Problem:** This person explains the issue(s) we are collectively concerned about
- Personal Story: This person briefly tells their own story as it connects to the *problem and/or the ask*.
- The Ask: This person will ask the elected official to fund/ co-sponsor/ etc. something specific.
- Note Taker: This person will take the office's contact info and write up brief notes.

Example of Successful Policy and Program Advocacy from NYS Provider Steve Miccio, CEO, PeopleUSA

#### **Infusing Recovery Based Principles into Mental Health**



September 2004

#### **Comprehensive Support for Overall Wellness**



People USA offers a diverse array of programs and services designed to meet the unique needs of those we serve. Each program is tailored to support personal journeys towards behavioral health and wellness.

**New York** Health Equity Reform 1115 Medicaid Waiver Goals



Goal: Advance health equity and reduce disparities.

**MM** 

#### Improve population health



Improve access to health-related social need (HRSN) services



Strengthen the workforce

# Alliance Waiver Community Connection Initiative

- Interested in learning more about the waiver and how your organization can connect with your regional Social Care Network?
- Connect with the Alliance to join our upcoming Waiver Community Connection Education webinars and in person events
- Contact Brett Scudder at <u>brett@scudderconsulting.com</u> or Luke Sikinyi at <u>LukeS@rightsandrecovery.org</u>
- Follow our Enews to see announcements for the upcoming webinars and other events!

Join us for The Alliance's 28<sup>th</sup> Annual Legislative Day in Albany!

We will be at The Egg in Albany on March 5th, 2025!

#### The Alliance for Rights and Recovery

/ww.rightsandrecovery.org

# Questions?



# Every little action causes a reaction!

#### Register to Vote!