



NWIC

National Wraparound
Implementation Center

Advancing Systems  *Enhancing the Workforce*  *Improving Outcomes*

Policy Considerations for Youth and Family Voice in Systems of Care

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Objectives

- Understand what is meant by engaging families and youth in policy—and the difference between systems-driven policy and youth/family-driven policy
- Explore methods to engage families and youth in both types of policy work
- Review key considerations to meaningful engagement with families and youth in policy development and implementation

Introductions

- Who is in the room?
- What is your perspective? (Are you a family member or a youth or young adult? Are you a policymaker or administrator?)
- What do you hope to get out of today's session?

WHAT IS POLICY AND WHY DOES IT MATTER?



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Defining Policy

The Centers for Disease Control & Prevention (CDC) defines policy as “a law, regulation, procedure, administrative action, incentive, or voluntary practice of governments and other institutions.”



<https://www.cdc.gov/policy/analysis/process/index.html>

Understanding Policy

- Policymaking happens in a context that is dynamic and complex
- Policymakers are influenced by many factors such as budget, constituents, science, experts, anecdotes, recent events and campaign cycles.
- Effective advocacy is a major factor that influences policy.

Change & Values in Policy

“All policy means choice involving change. **Policy by its very nature implies that we ‘believe we can affect change in some form or another.** We do not have policies about the weather because, as yet, we are powerless to do anything about the weather.’¹ Yet, precisely because it cannot escape the constraint of choice involving change, precisely because it is **action-oriented and problem-oriented, no policy can escape from values, ideologies and images of what constitutes the ‘good society.’”**

Reisman D. (2001) The Definition of Social Policy. In: Richard Titmuss. Palgrave Macmillan, London. P. 29-30. *Emphasis added.*

FAMILY- AND YOUTH-DRIVEN POLICY

Building the Rational: Youth and Family Driven Policy

- Because mental health challenges are common...
 - One in four adults experiences a mental health disorder in any given year, including our returning troops
 - About 10 million Americans, or one in 17, live with a serious mental illness, such as schizophrenia, major depression or bipolar disorder
 - One in 10 children and youth have a serious mental health condition
- Because treatment works, but most go without...
 - Fewer than 1/3 of adults and 1/2 of children with mental health needs receive any level of treatment in any one year
 - There are long delays—an average of eight to 10 years—before people get help for symptoms of mental illness

Youth & Families often do not have a voice of their own in policy decisions that affect them.

Value of Youth and Family Voice

Changes

- Institutional culture and practice

Builds

- Awareness and understanding
- Self efficacy
- Sense of community
- And implements new policies that better serve youth and families

Value of Youth and Family Voice

Improves

- Individual and organizational outcomes
- Outcomes for children and their families

Informs

- Research and evaluation
- Public policy

Transforms the system

Why does it matter?

- Youth and Families are the experts on their own lives, experiences, and preferences.
- If policymakers don't hear from youth and families, they assume everything is okay!
- Youth and families can
 - Influence policy
 - Improve services
 - Increase funding for needed programs (and highlight programs and practices that are duplicative, unnecessary, or even harmful)
 - Educate policymakers, legislators, and researchers on what makes a difference!

HOW DO POLICYMAKERS ENGAGE FAMILIES AND YOUTH?



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Systems-Driven Policy Initiatives

Goal is to have meaningful engagement with youth and families to **shape, respond to, and improve** policies and protocols (proposed and in implementation).

Don't confuse *what* you are trying to achieve with *how* you need to achieve it!

The What

- Have youth and families at the table for the design and implementation of policies and protocols, including initial development and drafting
- Have youth and families provide feedback on internal policies and protocols or new approaches or initiatives
- Have youth and families participate in system-level quality improvement initiatives, including development of tools and participating in site visits
- Have youth and families partner in legislative initiatives and engagement with funders

The How

- Contract with Family-Run Organizations (FRO) and Youth-Run Organizations (YRO) for ongoing participation and/or to provide stipends for individuals to participate
- Conduct Focus Groups, Listening Sessions, Interviews, and/or Surveys
- Hire family members and youth
- Support youth and family advisory boards (including staff support, reimbursement for transportation and child care, and providing sufficient preparation prior to and follow up after meetings)

Youth & Family Considerations

Individual

- Readiness & Skill Development
- Leadership and advocacy
- Strategic sharing training
- Public speaking
- Understanding policy at multiple levels and its impact on youth and families

Organizational

- Commitment to supporting youth and families in the process
- Infrastructure to collect & access data to support the message
- Ability to convene and partner with other stakeholders
- Leverage partnerships & relationships

What has worked well for your
community?
What has *not* worked well?

FAMILY- AND YOUTH-DRIVEN POLICY ENGAGEMENT



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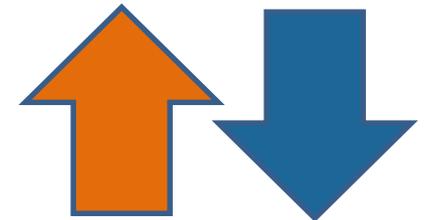


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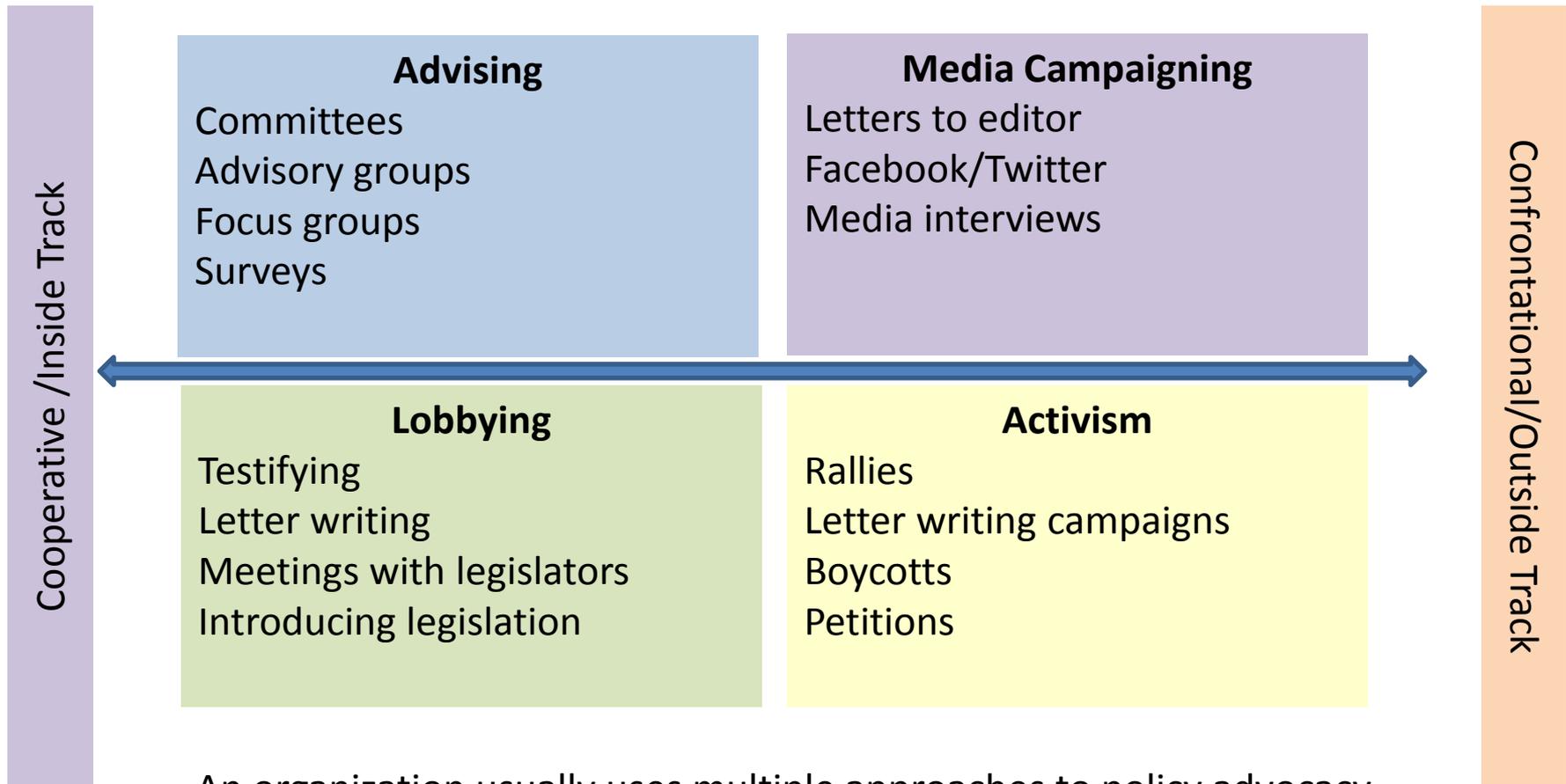
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Top Down Bottom Up

- Top-down approach – may be implemented by virtue of a statute, executive order, or court decision, guided by mandated procedures i.e. procurement
- Bottom-up approach – families and youth participate in decision-making about the strategy and in the selection of the priorities to be pursued in their local area.
- Bottom-up approach should not be considered as alternative or opposed to top-down approaches
- Combining and interacting with them, in order to achieve better overall results.



Approaches to Changing Policy



An organization usually uses multiple approaches to policy advocacy.

Parents/Youth as Advocates

Parent/youth leaders are:

- connected to each other and their communities;
- authentic in their understanding of issues;
- informed about the issues they are looking to address;
- collaborative in seeking positive solutions;
- persistent over time and dedicated to achieving their goals; and
- effective in producing meaningful change.

Annie E. Casey Foundation, Parents as Advocates: Influencing Policymakers to Improve Public Policies for Families, November 14, 2014, Patrice Cromwell

CONSIDERATIONS



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Considerations

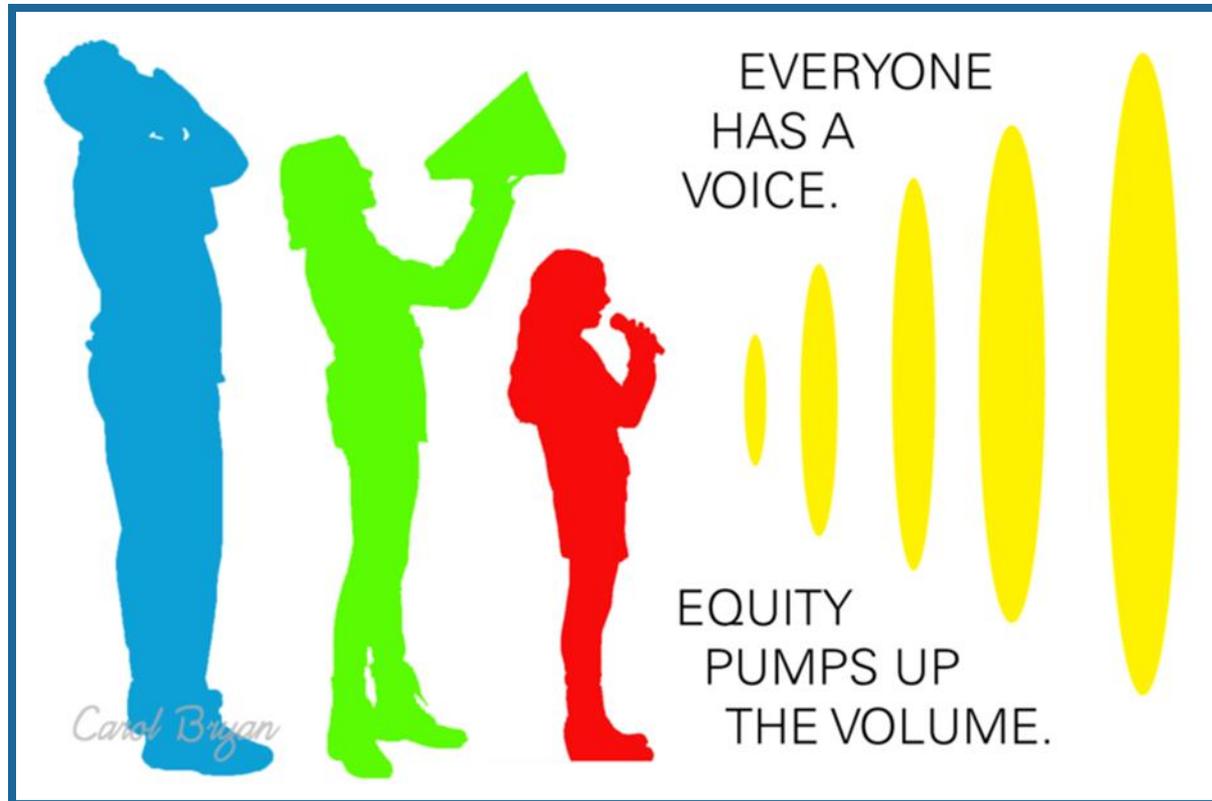
- Who needs to be at the table?
- How do we prepare them in advance?
- What supports do they need?
- Many families/youth, not one or two
- Provider vs advocate
- Inside vs outside
- Organizations or individuals
- The payoff



Effective Collaboration

- Build and maintain trust
- Agree on core values
- Focus on common goals
- Respect the knowledge and experience each person bring
- Assume the best
- Recognize strengths and needs; identify the best way to maximize participation of each partner
- Honor all voices
- Share decision making

Equity in Decision-Making



Strategies

- Many voices – not one
- Outreach
- Resources
- Right fit
- Support

FAMILY AND YOUTH ENGAGEMENT IN POLICY MAKES A DIFFERENCE!



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The Able Act

- Families went to Congress in 2006 saying that families caring for a child with special needs were told their child could not have assets over \$2,000 or they would lose benefits like SSI. Medical bills not covered by MA had to be paid by families, like dental bills, hearing aids
- Individuals like Sarah Wolff also spoke out that she could not save for college.
- The Stephen Beck Jr. Achieving a Better Life Experience or Able Act was passed in Congress in 2008 creating tax-free savings accounts for individuals with disabilities to cover qualified expenses such as education, housing and transportation.

What are your success stories?

Resources

- Community Toolbox: <http://ctb.ku.edu/en/best-change-processes>
- *During Meetings I Can't Stand It When...A Guide for Facilitators and Team Members*. Portland State University: <https://www.pathwaysrtc.pdx.edu/pdf/proj3-facilitator-guide-2013.pdf>
- Koroloff, N., Friesen, B., & Buekea, N. (2016). Advice to Young Adults from Young Adults: Helpful Hints for Policy Change in the Mental Health System. Research and Training Center for Pathways to Positive Futures, Portland State University: www.pathwaysrtc.pdx.edu
- Koroloff, N., Friesen, B., & Buekea, N. (2017). *Changing the rules: A guide for youth and young adults with mental health conditions who want to change policy*. Research and Training Center for Pathways to Positive Futures, Portland State University: <https://www.pathwaysrtc.pdx.edu/changing-the-rules>
- Roles of Family-Run Organizations Infographic
<http://www.fredla.org/wp-content/uploads/2015/09/FRO-infographic-1.pdf>
- Role of Family-Run Organizations in Systems of Care
https://www.nasmhpd.org/sites/default/files/Assessment%20%237_The%20Role%20of%20Family-Run%20Organizations%20in%20Systems%20of%20Care.pdf
- Ten Tips for Outreach to Families Infographic
http://www.fredla.org/wp-content/uploads/2015/09/Outreach-to-Families_FREDLA-2016.pdf