

Mental Health Policy Change by Youth and Young Adults

To some people, “policy” seems like a mysterious and perhaps boring topic, compared to the busyness and intensity of everyday life. However, a growing number of youth- and young adult-led groups have shown how policy issues can

influence their choices and their lives in critical ways, and that they can have substantial influence on policy. Policies may be general, and apply to all people in society (e.g., traffic laws), or they may specifically focus on particular groups of people, such as people with a mental health condition or criminal record (e.g., policies about housing or employment). Organizations such as Youth M.O.V.E. and other groups led by young people with mental health concerns have demonstrated that they can have important roles in changing flawed policies to make them better or to put positive policies in place. Examples of policy issues that might need change include rules about eligibility for housing or rent subsidies; increased young adult choice in treatment; greater availability of peer services; or more services, supports, and funding for young people entering college, among others.

***Policy** – a rule, decision, or regulation on what a person or a group of people can say, do, or have. (Friday Night Live, 2012).*

Policy can take the form of laws, regulations...and funding priorities about a given topic enacted by a government entity or its representatives (Kilpatrick, 2000).

What is this guide about? Who is it for?

This guide provides information about policy and policy change in mental health and other human services for young adult groups who want to be



directly involved in policy change activities. Some of the many ways that young people can be involved in policy work include serving on advisory committees that consider areas where policy change is needed, participating on groups convened to review contract language about youth-related issues or serving on groups charged with developing rules and regulations to support recent policy change. A number of manuals or handbooks address these important roles, although few of them are specifically focused on mental health.

This policy guide is written for youth- and young adult-led groups and organizations that want to make changes in policies that affect them and other

transition-age youth. The intended audience for this guide is youth and young adults working together within a group or organization to make specific change, usually in partnership with other agencies, groups, or organizations. In fact, young adults who have been involved in successful policy change efforts often emphasize that their groups were able to accomplish their goals because they had supportive partnerships with other organizations.

Why is this guide focused specifically on issues of concern to youth and young adults with mental health conditions?

- Young people with mental health concerns should be involved in policy change because their lives are directly affected by a variety of policies (laws, rules, and funding priorities). Although there are several policy manuals focused on youth, none specifically addresses issues related to young people with mental health conditions.
- Transition age youth who have lived experience often have much to share about policies that have supported or interfered with their hopes and goals.
- The mental health system is complex, and anyone who wants to make policy change will need to understand the complicated tangle of laws, rules, funding sources, and interagency relationships, as well as the history of how past decisions and social movements have shaped the current system.
- A great deal of stigma about mental health conditions still exists, and successful advocacy for change involves learning how to address and overcome stigmatizing attitudes and beliefs, especially those

held by people who have the authority and access to make the needed change.


- Mental health services and supports are largely funded by federal Medicaid dollars which influence local and state policy through eligibility and reimbursement policy. It is important to be aware of the potential influence of federal laws and funding on what may at first seem like local or state issues.

Is there research about the policy change activities and outcomes of youth- and young adult-led groups and organizations?

Yes, during 2015–2016 youth and young adults from nine youth- and young-adult-led organizations, along with their adult allies, participated in a study called “Stepping Up: Successful Advocacy by Youth and Young-Adult Organizations.”¹ The study focused on their efforts to change policies in their states and communities. Through face-to-face or telephone interviews these young adults provided much valuable



information about their efforts to change policies that were important to them. More information about this study can be found at <https://www.pathwaysrtc.pdx.edu/pdf/pres-Proj4-SPAC-Tampa-2016-1.pdf>.¹

This guide includes direct quotations from the young people who were a part of the “Stepping Up” study along with their stories about the activities, successes, and challenges faced by the youth groups. Youth and young adults who were part of the study also made recommendations for others who want to improve the lives of transition-age young people, and much of this advice is included in this guide. Whenever quotations or findings from the “Stepping Up” study are included, this symbol will be used to alert readers that we are talking about “Stepping Up”: 



STEPPING UP

“I actually got to see with my own eyes that youth can have a voice ... and other people who are adults will actually take [their ideas] into consideration and actually change it.”