

WEEK 9 – OVERVIEW OF PARENTS, FAMILY MEMBERS, AND ADVOCATES IN POLICYMAKING

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Welcome to week nine of MHS 6706 Child and Adolescent Behavioral Health Policy. This week we are discussing the role of parents, family members, and advocates in child and adolescent behavioral health policy. Not only are we going to include the history of parents, family members, and advocates in policy making, we will also examine the role of narratives in policy making and how including a wide range of stakeholder perspectives can create more effective advocacy in support of issues in child and adolescent behavioral health policy.

As you reflect on the timeline presented during the week two lecture, there have been a lot of milestones in child and adolescent behavioral health policy. Of all the milestones perhaps the most important is the formal acknowledgement of the importance of parents, family members, and advocates in policy making. We thought we would start out with a review of several of the parent/family member and advocacy organizations. Remember to look at the use of language. In many cases we are using the language of the groups to describe their foci for children and adolescents with behavioral health problems.

The oldest extent advocacy group in the United States is Mental Health America formally known as the Mental Health Association-- MHA-- which was established in 1909 by former mental health patient Clifford W. Beers. It's many accomplishments include advocacy for work for the National Mental Health Act-- the commission on mental illness and mental health-- the Community Mental Health Centers Act, and the Protection and Advocacy for the Mentally Ill Act.

Two important reports on children and adolescents supported by MHA included the report of the Invisible Children Project and the neglect and over institutionalization of children with behavioral disorders and the first ever bullying survey of children that reported that 78% of teens who are gay or thought to be gay were teased or bullied in their schools and communities. Originally founded in 1979 as the National Alliance for the Mentally Ill, NAMI-- N A M I-- is one of the best known grassroots advocacy organizations in the United States.

The NAMI Child and Adolescent Action Center, or CAC, works to improve the lives of children and adolescents living with mental illnesses and their families. The CAC's policy focus is broad, addressing early identification and intervention of mental illnesses, lobbying federal and state legislators, and partnering with organizations to meet the needs of children and adolescents with behavioral health problems.

Currently it is focused on passage of the following federal bills-- The Mental Health and Schools Act and the Keeping All Students Safe Act. The National Federation of Families for Children's Mental Health is a national family run organization focused on the issues of children and youth with behavioral health needs and their families. Founded in 1989, the Federation of Families began with 75 members in 26 states. Today it has over 120 chapters across the nation providing training and technical assistance to substance abuse and mental health services administration funded systems

of care grantees, provider organizations, and state agencies. In addition, it has been a leader in developing curriculum to training family members and providers all across the country on the principles and values of family driven care.

A parallel effort is the development of national standards for a parent support provider certification process. Perhaps one of the most exciting efforts of the National Federation is its launch of the Youth MOVE national into an independent national youth organization. An action that is particularly appropriate as we examine the issues in child and adolescent behavioral health policy. Active Minds is a non-profit organization that helps students to speak openly about mental health problems.

Founded in 2000 by Alison Malmon, a student at the University of Pennsylvania, after the suicide of her brother. She founded Open Minds to combat the stigma of mental illness and encourage students who need help to seek it. As the program grew at other campuses, in 2003 it was renamed Active Minds. Today it has over 400 campus chapters and is guided by a board of directors and a national advisory committee made up of experts in the field of mental health and a student advisory committee made up of leaders from student campus chapters.

On the 17th of July in 1990 President George Bush designated the 1990s as the decade of the brain. The National Institute of Mental Health and the Library of Congress jointly introduced members of congress, their staffs, and the general public to cutting edge research on the brain and its applications to improving the lives of prisoners with mental illnesses. Seven years into the decade of the brain, U.S Surgeon General David Satcher authorized the preparation of mental health, a Report of the Surgeon General.

This was a major breakthrough for persons with behavioral health problems, their family members, and advocates. In the United States the office of the U.S Surgeon General is charged with the protection and advancement of the health of the nation through educating the public and to articulate scientifically based health policy analysis and advice of the President and the Secretary of Health and Human Services on the full range of critical public health, medical, and health system issues facing the nation. He or she reports to the assistant secretary for health, who is the principal adviser to the U.S Secretary of the Department of Health and Human Services on public health and scientific issues.

As the Surgeon General is responsible for the protection and advancement of the health of the nation, his or her reports play a major role in raising awareness of important health issues and generating public health initiatives. The mental health report was 487 pages that pull together the evidence base of the current knowledge and the prevalence, diagnosis, treatment, and outcomes of mental and substance use disorders.

Donna Shalala, then secretary of the U.S Department of Health and Human Services, called it a seminal report that will allow us to take what we know and to advance the state of mental health in the nation. More importantly, the U.S Surgeon General's report is more than just a professional or governmental report. It clearly acknowledges the role persons with mental illnesses and their family

members play in policy making. The report explicitly states the importance of these consumer movements to policy making. In the Secretary's preface of the report she notes that consumers and others comprise the leaders in the field. And remember when this report was written mental health was the phrase used to address what we now call behavioral health.

Throughout its 487 pages the report emphasizes the importance of the consumer and family member movements as important mechanisms to bring their concerns and suggestions to the attention of providers, researchers, and policymakers. It is first introduced in chapter one with a more complete overview provided in chapter two. Its role in changing the delivery of services to children and adolescents is addressed in chapters three, four, and five.

One year later, in 2000, the report of the Surgeon General's conference on children's mental health was published. Reporting the conclusions and recommendations of over 300 participants, which included a wide range of stakeholders including youth and family members, professional organizations and associations, advocacy groups, faith based practitioners, clinicians, educators, health care providers, and members of the scientific community and to the health care industry. The intent was to create a national action agenda on children's mental health.

Robert Friedman, who was here in the department of children and family studies within the college, was an invited speaker and discussed issues surrounding systems of care. He was followed by Angelique Harris, the 19-year-old young woman who shared her personal experiences with mental illness and mental health delivery systems. Two of the other discussions for that session included Trina Osher -- Federation of Families for Children's Mental Health-- and Dr. Jane Knitzer -- Columbia University. Both of these are well known advocates. Then in 2002 two national workshops were held on the needs of persons with developmental disabilities.

The report of the Surgeon General's Conference on Health Disparities and Mental Retardation entitled Closing the Gap: A National Blueprint to Improve the Health of Persons with Mental Retardation provided a series of action steps, goals, assessment strategies that were loosely modeled after the Healthy People Framework. Now the National Institutes of Health and the Joseph P. Kennedy Foundation sponsored the workshop on emotional behavioral health in persons with mental retardation developmental disabilities research opportunities and challenges.

Opened by Mrs. Eunice Kennedy Shriver, a well known family member and advocate for persons with development disabilities, the workshop developed a detailed research agenda to examine the epidemiology, diagnosis, and assessment, and interventions. As well as the ethical considerations, research design, and research training needs to provide services. And to improve the quality of life for persons with developmental disabilities.

By 2003 the President's New Freedom Commission on Mental Health published Achieving the Promise: Transforming Mental Health Care in America a final report. Two subcommittees were established to focus on children and families and on consumer issues. In the consumer issues report recommendation 2.2 was explicit-- involve consumers and families fully in orienting the mental

health systems toward recovery. Again, we have the federal government emphasizing the role of consumers and family members in planning and assessing services at the local, state, and federal levels. And establishing a national paradigm, that of recovery for persons with behavioral health problems.

In 2005 the National Federation of Families for Children's Mental Health was asked to define the term "family-driven". It's family-driven definition is still used today across the country in the implementation of community based systems of care for children and families. Since 2003 there have been a number of parent/family member and advocate led initiatives, reports, and workshops to address the needs of children with behavioral health problems.

Most recently in 2013, President Obama and Vice-President Biden hosted a National Conference on Mental Health at the White House as part of the administration's national conversations to increase understanding and awareness about behavioral health. A new website was also launched from the conference-- mentalhealth.gov-- providing resources for those suffering from behavioral health problems and sharing success stories from those who received treatment. In addition, at this National Conference on Mental Health at the White House a number of interesting initiatives were discussed. Including the National Association of Broadcasters national public awareness campaign to reduce negative attitudes and perceptions about behavioral health problems to television and radio ads and social media.