

Advocating for Children and Adolescents with Mental Illnesses

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- Mental health parity

The mental health community has made tremendous strides over the last 20 years to eradicate stigma, demand policy change, and improve the lives of millions of children and adolescents with mental illnesses. Most of this has been accomplished through advocacy at all levels of government and was assisted by community involvement. However, addressing access to care for children and adolescents with mental illnesses is still a challenge. Despite 2 decades of dedicated effort, there remain many children and adolescents with mental illness without health insurance. Workforce shortages in child psychiatrists,¹ inadequate reimbursement of health care costs, limited government-supported research funding, and lack of coordinated systems of care result in persistent barriers to effective mental health care. Emergency rooms are still often the only resort for treatment. Building on past successes and working toward improvements within child mental health systems can be done by better informing our policy makers about needs and deficiencies in access to care and by urging our legislators to improve the lives of millions of children and adolescent with mental illnesses.

Advocacy is a challenging concept because there is no one set of instructions about where and how to begin and what constitutes effectiveness. Advocacy can mean many things, but fundamentally, it is about speaking out and making a case for something important and about supporting a cause. It can be political, as in lobbying for a specific piece of legislation, or social, as in speaking out on behalf of those without a voice. Legislators and their staff in our federal and state governments are often unaware of children's mental health issues. Child and adolescent psychiatrists may be instrumental in drafting, debating, and implementing the laws and regulations that govern child and adolescent mental health care, individually or together with

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organizations dedicated to the needs of children and families. Elected officials look to professionals for advice or recommendations for developing policy initiatives because their voice is one of authority and expertise in child and adolescent mental health.

The reasons for advocacy need to be explored. Fortunately, when more people get involved, wonderful things can happen. All the legislative victories of recent decades—educational rights for children with disabilities, state and federal mental health parity, environmental protection, child care for working parents—are the direct result of advocacy. Getting involved in advocacy will not always yield success, but being uninvolved never does so. People may think that they do not have time, may not know where to start, or may be intimidated, but advocacy can also be enjoyable. Advocacy includes working directly with legislators and policy makers, working with a school administration to meet the unique needs of the child, appealing against denial of specific treatment or formulary approval by the managed care company, and educating and collaborating with primary care physicians on appropriate treatments.

Three principles that need to be understood about advocating are that change takes time, persistence is absolute, and compromise is inevitable.

A new Congress begins every 2 years and new state assemblies typically begin each year. Each new legislature brings new faces and priorities, making reintroduction of bills a necessity. Showing persistence, building on what has been developed previously, and moving forward are important. The way to advance an agenda is often grounded in compromise and in the ability to create a strategy for future initiatives.

CHANGE TAKES TIME

Mental health policy issues are far from new; in fact, many issues have roots that go back 50 years or more. In health policy, as in other areas of policymaking, history has played out in often unexpected ways. In the early 1950s, it was unheard of to educate children with mental illness in the classroom. Throughout the late 1950s and 60s, laws, such as the Training of Professional Personnel Act of 1959 (public law [PL] 86–158), were enacted to help train leaders to educate children with intellectual disabilities. The Elementary and Secondary Education Act (PL 89–10) and the State Schools Act (PL 89–313) provided states with direct grant assistance to help educate children with disabilities. Finally, the Handicapped Children's Early Education Assistance Act of 1968 (PL 90–538) authorized support for exemplary early childhood programs and increased Head Start enrollment for young children with disabilities.² These and other critical federal laws paved the way for Congress to enact the Education for All Handicapped Children Act (PL 94–142) in 1975 (now called the Individuals with Disabilities Act), which began opening up educational opportunity for children with disabilities and their families.

In 1983, with a Congressional mandate and funding, the National Institute of Mental Health initiated the Child and Adolescent Service System Program. This program provided funds and technical assistance to the states and territories to plan and develop systems of care for children with serious emotional disturbance. In 1986, Congress passed the State Comprehensive Mental Health Services Plan Act that required all states to develop and implement plans to create community-based service systems for all persons with mental illnesses. Building on these successes, in 1992, Congress created and funded the Comprehensive Community Mental Health Services for Children and their Families Program; today, this program is the major source of funding for local systems of care development.

It is clear from this brief history that effective policy change takes time and its foundation is often rooted in other successful legislative initiatives.

PERSISTENCE IS ABSOLUTE

Time, patience, and perseverance will accomplish all things.

—Anonymous.

Advocacy can include activities like organizing a community march, writing a letter to the editor, testifying before your county board, or writing to or visiting one's elected officials. The most basic form of advocacy is just "speaking up." However, many will listen but not hear the message the first time, and continuing to speak up about the issue is vital to successful advocacy.

Clarity, brevity, and use of language that everyone understands, including those that are not experts on the specific issues, is important. Every communication, in person, by phone, or in writing, should have one basic message, for example, "There is a severe shortage of child and adolescent psychiatrists and this is how we can resolve it. . ." One should not be afraid to repeat this message until the right person listens.

COMPROMISE IS INEVITABLE: THE 80% RULE

There is tremendous exhilaration in "winning," but there is also a lot of satisfaction in just advancing a mission. When advocating at the local, state, or federal level, change takes time. Often, only part of the requested change will happen, but with the right strategies, it can be a step and sometimes a leap forward.

Very few pieces of legislation are passed with 100% of what any one constituency wants. Wyoming Senator Mike Enzi said that he hoped to help overcome partisanship in Congress with his "80 percent rule"—his belief that Democrats and Republicans can get more done by focusing on the 80% on which they can agree.³ Often constituencies advocating for a piece of legislation say that they can support most of the provisions on the table, but there is 20% that they cannot support or that may be missing. The problem for so many reformers is that some are likely to "fall on their sword" over the 20% and kill the entire piece of legislation. Advocates play a critical role in identifying the points of consensus between the constituents and recommending legislation based on compromise, rather than abandoning the potential change altogether.

The Paul Wellstone and Pete Domenici Mental Health Parity and Addiction Equity Act of 2008⁴ provides an example of a successful legislative act that incorporates the 3 components of waiting for positive change, being persistent, and facing the inevitable need for compromise. From the early 1990s to 2008, small steps were made to improve the discrimination against people with mental illnesses in their health insurance coverage. In its proposal for health care reform in 1994, the Clinton administration attempted to shift the burden from the consumer to the public or private insurance sectors by introducing a mental health parity law.⁵ The Clinton health reform bill never advanced but it was instrumental in a trend toward mental health parity and the redistribution of mental health care provided by health maintenance organizations. In September 1996, the Mental Health Parity Act (MHPA) of 1996 was introduced. This was the first legislation to make mental health annual or lifetime dollar limits equal to those that applied to medical or surgical benefits. After a failed attempt to amend this bill to an overall health care bill, it was attached to a Veterans and Housing Appropriations bill and passed, but only after significant compromises. In 2001 and subsequent years, legislation was enacted to expand the 1996 mental health parity law. Although some of the bills were passed in one chamber, the other chamber did not approve them, and thus the bills did not become law. For years, laws that extended

the time period of the 1996 MHPA were the only legislative advances in mental health care.

However, between 1996 and 2007, two different constituencies, the mental health community (providers and family advocates), and the health insurance companies were discussing how they could work together to improve health insurance coverage for persons with mental illnesses. In 2008, these efforts led to the enactment of the Paul Wellstone and Pete Domenici Mental Health Parity and Addiction Equity Act. This too did not pass without compromises, such as requiring health plans to continue coverage of the disorders and treatments that they currently cover, rather than mandating that health plans provide coverage for every mental health disorder published in the diagnostic and statistical manual of mental disorders. However, through the persistence of the mental health community group, with the passage of the act, imposing different treatment or financial limitations in health plans on mental health benefits from those applied to medical and surgical services is now prohibited. The legislation successfully closed the loopholes that allow discrimination in the co-payments, coinsurance, deductibles, maximum out-of-pocket limits, and day and visit limits.

JOINING TOGETHER TO EFFECT CHANGE

Identifying Allies

Demonstrating to elected officials that one is representing many constituencies, institutions, and voters in one's community is important. To begin advocacy efforts, it is important to scan the environment for allies and opponents. For child and adolescent psychiatrists, likely allies are the families and youth being treated. Other pediatric physician colleagues, child psychologists, social workers, school counselors, and teachers can also be allies in advocacy. Discussing the issues of access to mental health care with these allies will help to illuminate how a policy might affect child and adolescent psychiatrists, families, and other professionals.

Professional organizations, such as American Academy of Child and Adolescent Psychiatry (AACAP) are also allies and resources. Professional organizations have staff to monitor policy issues, alert the membership to upcoming legislation and regulatory action, and meet with members of Congress on the organization's behalf. They can also arrange meetings with elected representative at the state and federal levels. Professional organizations often collaborate with other groups to draw on everyone's knowledge and jointly activate numerous organizations at the grassroots level. The larger the number of cooperating individuals and organizations, the more effective advocacy efforts will be.

Principles of Legislative Advocacy

Timing advocacy to influence legislation is an important skill. Once an issue is decided by vote, it is difficult, often practically impossible, to reverse the decision until the next year or the next session of Congress. As mentioned earlier, passing legislation can take a long time and just because a piece of legislation is not advancing, it does not mean that it is not supported. Other influences, such as policy cost, political wrangling, or competing priorities, can hold up a piece of legislation. The shortage of children's mental health professionals has been a priority of the AACAP for many years. Legislation called the Child Healthcare Crisis Relief Act,⁶ which provides loan forgiveness and scholarships to individuals who study in graduate and medical programs in child mental health, was first introduced in 2004 and reintroduced in subsequent years. Even though the bill gained support each year and ultimately was amended to another

piece of legislation, it has not been adopted. With the focus on mental health parity legislation last year, discussions about this bill were put on hold. However, the passage of the MHPA provides an opportunity to move this legislation forward using the argument that with equal insurance coverage, more individuals will be seeking mental health care; consequently, the shortage of children's mental health professionals is a real concern and an impediment to treatment access.

Once policy is introduced, it is important to consult allies and decide on a strategy. There are 100 members of the US Senate and 438 members of the House of Representatives, including the delegates from the District of Columbia and the US territories, which makes the task of educating them about a specific policy issue daunting. A targeted approach is paramount to making the best use of resources.

Firstly, it is important to decide which elected representatives might be "champions" for the legislation. Getting bipartisan support is essential. The mental health community has wonderful champions in Representative Patrick Kennedy, former Representative Jim Ramstad, Senator Edward Kennedy, and former Senator Pete Domenici. All have shown a commitment to improving the lives of children and adolescents with mental illness. Secondly, it is important to know which committees and subcommittees have jurisdiction over the legislation. If legislation is introduced and referred to a committee, this does not mean that the committee will discuss it. It is up to advocates to inform policy makers about its importance and garner support.

Once the champions are recognized and strategies are set, there are various ways to communicate the message. Avenues for communicating with public offices include:

- Visiting, telephoning, writing, or sending a fax or e-mail to the congressional district or Washington, DC office
- Attending rallies, fundraisers, or town hall meetings where the champions are expected to speak
- Inviting elected officials to a local child psychiatry meeting, hospital, or clinic
- Writing a letter to the editor for placement in a local or state paper and taking advantage of other media opportunities

Communicating with Legislators

Research has shown that almost half of all Americans had been in touch with a member of congress in the last 5 years.⁷ It was in the mid-1990s that congressional offices got e-mail addresses and before that, most communication was done by mail, fax, and telephone contact. The advent of the Internet and other wireless communication continues to significantly ease becoming involved in the public policy process. The Internet and e-mail have also provided grassroots and professional organizations with new and exciting opportunities to organize around issues and to access and share information. President Barak Obama's 2008 campaign took full advantage of various technologies to create a "netroots," that mobilized voters across the country into a unified voice.⁸

Many who contact Congress are motivated and assisted in doing so by professional and advocacy organizations. These organizations provide significant guidance and assistance with the process of transmitting, and often of drafting, the communications. The AACAP provides specific language and other talking points for e-mail, fax, or telephone communication.⁹

The most effective way to quickly communicate your message to your elected official depends on the specific legislators and their staff. Although members of Congress genuinely want to hear from constituents, the rising volume of communication from

them has overwhelmed their collective staff. Because congressional offices function basically as independent small businesses, each office's staff have had to decide how to manage its messages. E-mails from personal or work (if appropriate) computers are always best. Some offices have concluded that advocacy campaigns of identical form messages that are not sent from constituents' addresses or under their name do not warrant a response.¹⁰

E-mail and telephone is the easiest and most standard way to communicate your message, although there is no substitute for face-to-face communication with one's elected official or staff. This often cannot be done on a weekly or even monthly basis but should be done once a year. Elected representative are available for meetings in their district offices within the state or in Washington, DC. AACAP and other professional advocacy organizations can assist with making the appointments and provide material for the meeting. Congressional representatives are very busy and may not be able to meet with their constituents for long periods or at all. It is important to get to know not only elected officials but also their staff, who often do the "real," behind-the-scenes work. They are often more knowledgeable than the representative about one's issues. Congressional staff are highly valuable to their bosses and are essentially tasked with prioritizing the many request made by constituents. Interaction with the staff is often the critical link in making certain that the issues are seen by the representative.

Many professional organizations have organized days to visit elected representatives. For the last 4 years, AACAP has held an advocacy day and invited child and adolescent psychiatrists from across the country to Washington, DC to learn about the legislative process and meet with their Congressional offices. It is important to invite allies, such as families, to join the meetings. By including different viewpoints, the meeting will be seen as representing multiple constituencies. By meeting face-to-face with elected representatives or their staff, communication lines are opened and dialog can begin. Local professionals often become their experts and are sought out for advice afterwards.

Important points to remember when calling, sending e-mails, or meeting elected representatives include

- Mentioning that one is a constituent and a child and adolescent psychiatrist and mentioning one's other professional affiliations, such as affiliation to a large university, hospital, or business in that district or state
- Keeping the message simple, using language that everyone will understand, and spelling out acronyms such as GME (graduate medical education)
- Including a personal anecdote about why taking a specific action is needed; for example, when asking for support with legislation to address the shortage of children's mental health professionals, providing information on the average wait time for a new patient to be seen due to an already excessive case load

When meeting with an elected official, visual aids or charts are powerful tools to emphasize key points. One must be prepared for follow-up questions. Not knowing information that they want is acceptable, because getting back to them with it is a great way to reconnect and continue the dialog. Postmeeting contact via email or telephone is important for reinforcing the message.

Many members of Congress are in their home district or state on the weekends and also take designated recesses throughout the year. During these times, they often attend town hall meetings, state fairs, fundraisers, and other public events to talk with their constituents. These are ideal opportunities to ask questions about specific

policy issues. For a more intimate acquaintance with elected officials and to educate them on specific policy concerns, invite them to a local professional organization. Presenting them with an award is another avenue for showing support.

Working with Media

The media are an extremely powerful tool for policy change. Public awareness will help build a larger constituency for one's issue and further strengthen advocacy efforts. The goal of connecting with the media is to influence behavior or policies and to offer information on problems and solutions that otherwise might be ignored.¹¹ Two media tools include writing a letter to the editor and developing a relationship with a local journalist, requesting that an editorial be written. Although repeating statistics on a specific topic is not media advocacy, using those statistics to push for stronger laws or enforcement of existing ones is considered so. Elected officials and their staff watch television, listen to the radio, and read their local newspapers to better understand what issues are "hot" in their area. To keep specific issues in people's minds, getting journalists' attention, understanding what they want, and making those issues newsworthy is important. No opportunity must be missed to publically acknowledge a legislator's commitment to one's issues through a letter to the editor. Too often, legislators only get recognized for mistakes; if they are supportive of one's issues, a public acknowledgment may encourage other elected officials to be aware of the issues and possibly support them.

STATE LEVEL ADVOCACY

Advocacy on the state and local level is as important as work on the federal level. Today, the relationship between the states and the federal government in shaping and implementing public policy and the connection between federal and state public policy is becoming more evident. Because of this environment, public policy advocacy is critical at the state and federal level. Many laws and regulations that have the biggest impact on our everyday lives are passed at the state and local level. When a program, such as the State Children's Health Insurance Program, is passed by Congress, it is state legislatures that decide on how it will be implemented in their state. Likewise, because the constitution relegates basic police powers to the states, policies on juvenile justice and offenders with mental health problems are written and implemented at state level.

The methods for communication with one's state officials is similar to federal officials, however, there are some differences:

- Elected and appointed officials are more approachable.
- Public testimony is often sought.
- If a bill gains momentum in one state, it is easier to pass in another.

Elected and appointed officials often live on a day-to-day basis in the community that they represent. They are more accessible and approachable and taking advantage of this is important. It is estimated that state legislatures consider over 100,000 bills a year. Many state elected officials do not have a large staff, if any at all. With the vast number of bills introduced, no legislator is an expert, and advocates for child and adolescent psychiatry can be a valuable tool.¹² Committees often hold hearings where members of the public can give brief testimony and act as expert witnesses—another avenue for one's message to be heard. If legislation catches on

in one state, it is often easier for another state to pass similar legislation. This gives advocates the opportunity for faster advancement of their legislation.

SUMMARY

Anatole France said , "To accomplish great things, we must not only act, but also dream, not only plan, but also believe."

The political process is most often a marathon and rarely a sprint. Persistence is needed to advance all policy objectives. Professionals, such as child and adolescent psychiatrists, play an important role in the lives of countless youth and their families across the country. Experts in child and adolescent mental health issues have the opportunity to influence policy change at all levels of government. Becoming involved in future policy changes can yield improvements in the health care delivery systems, increase in numbers of children's mental health professionals, and increases in funding for child and adolescent mental health.

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