MHA PA
Mental Health Association in Pennsylvania
An Affiliate of Mental Health America

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Good afternoon and thank you for this opportunity to give public testimony on youth's mental health in Pennsylvania.

Framing the Issue

Youth, aged 14 to 21, are perched precariously between the adult and child mental health systems in Pennsylvania and nationally. They are served by a multiplicity of often poorly coordinated and configured systems and services. Youth and their families often find themselves in constant conflict with systems designed more for the systems convenience and operated from an outdated vantage point developed before the significant research conducted during the last two decades on what promotes mental health in youth, children, and families, and what is effective when that mental health is compromised. Tossed from system to system, and more restrictive and punitive services as less intensive services fail, youth are medicated and under-educated, and too frequently leave for adult world with no clear handle on the tasks they were supposed to master to be able to navigate the world on their own.

First, let me introduce myself and my role in this landscape. My name is Wendy Luckenbill and I am the Child Policy Coordinator for the Mental Health Association in Pennsylvania, which is the state affiliate of Mental Health America, formally the Mental Health Association in America. The Mental Health Association in PA is a membership organization which represents our 17 local affiliates who in turn represent most of PA, including all five major geographic areas and every mid-size and large urban area in the Commonwealth. At the state level, we work promoting mental health for children, youth, and adults, through advocacy, education and public policy.

I come to you today to speak from the family and youth perspective, on the state of current mental health services, including prevention and general wellness services. Each year for the last 2 decades, I have worked with families and their children in order to access needed services and supports. Additionally, I have partnered with them to develop and oversee public policies and programs which will be responsive to their needs.

A clear take-away from my work is that where families and their children are receiving early and evidence based services, there are dramatic and long lasting benefits. However, as the PA Legislature's own report found in 2006, children and their families often do not find those services, due to the complexity of their configuration and delivery. I will address this report later in my testimony. The good news is that we know how to promote and care for children and youth's mental health. Additionally, in Pennsylvania, we have a fiscal structure that supports public mental health services, although those services traditionally focused primarily on acute need rather than the prevention end.

The challenge becomes how to mobilize political will, and engage the community in the work of bringing to scale evidence based practices for children, youth and their families, and dis-incentivizing outdated services which are at best ineffective and at worst do harm. A discussion of such an effort begins with a recommendation from the PA Legislative Budget and Finance Committee's Report which is more fully cited below. This report found that we needed to develop a comprehensive plan which would provide for a continuum of services for children, youth and their families, and would be accessible and provide the most effective services in the least intrusive, least stigmatizing and restrictive manner.

Such a plan would most certainly identify services like Psychiatric Residential Treatment as a response which is not effective and which isolates and developmentally impedes youth with acute mental health needs. In contrast, there is a growing body of interventions are evidence based, and focus on healing and growing those developmental competencies that children and youth need to be productive contributing members of society. These services are less restrictive and markedly safer and more effective for the child, the family and the general community. These community-based services, ironically, provide a much higher level of clinical care than what is available in Psychiatric Residential Facilities (PRTFs). PA recently mandated national accreditation for PRTFs, but accreditation standards still allow these costly placements to provide services primarily by high school and bachelor level staff, often with no actual mental health training beyond on the job experience and employee mini-courses. A youth in a PRTF may see a master's or higher level mental health clinician 15 minutes or less a week. This differs significantly from community based evidence based services where masters or higher mental health clinicians provide intensive, often daily care. While these services can be as costly as residentially provided care, when they are provided with fidelity to the research model, they are significantly more effective, resulting in less utilization of service overall and better outcomes for the youth.

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The Face of Youth Needing Care

Let me pause to tell you two few brief stories of youth I have helped in the last few months. Both youth were residents of Pennsylvania publicly funded Psychiatric Residential Facilities.

The first youth was a 16 year old who had been in the facility for 8 months and was due for discharge. His mother called the MHAPA seeking assistance. He had been placed in the facility because he suffers from Serious Depression and would not go to school. His discharge was being postponed because although he was meeting most of his treatment goals, and was a model resident, he was still not meeting his educational goals. In a meeting with his parents and therapist, it was mentioned that he had significant neurological problems that made schoolwork difficult if not impossible for him, especially without major accommodations and interventions still not being provided. After years of not receiving this support, he was in fact responding normally to unreasonable demands. It is probable that early diagnosis and response to this youth's needs from the education and mental health systems, when he first had trouble in elementary school would have prevented the full court press that he now found himself in. That is- committed by the Education, Mental Health, Child Welfare and Juvenile Justice systems to a residential facility because of the truancy charges his now uninvolved home school district had pressed on him, and consuming the highest end, highest cost services offered by the mental health system.

The second youth I saw on an advocacy visit to a PA residential facility. The youth was 20 years old. He was sitting on the floor, surrounded by comic books. The staff explained that he had graduated from their onsite school, and they did not have any day program for him, so they had assigned him to the janitor so he would get some job skills. That was the extent of his vocational training and support. The staff said they thought it was an inadequate solution and he needed much more, but that was all they could figure out. This staff was the unit supervisor and had a law degree. On my questioning, she admitted she had never heard of the Office of Vocational Rehabilitation, which provides services to transition age youth including operating a residential job training facility, Hiram G. Andrews Center, where the youth could have continued to work on his mental health needs, in a coordinated program that supported his acquisition of needed life competencies. Certainly, the janitorial staff does not have the training or skills to be preparing this young man for employment yet alone the complexities of an independent adult life, coping with ongoing disability. There was no discharge plan in place, and the assumption was that he would live in this facility until he aged out at 21, being dropped unprepared into adult life, and an adult disability system that was far different from the bleak but totally structured existence he had lived for the past five years. Sadly, the youth told me about how hard it was to live in this place, with nothing to do, and the fear of his peers "losing it" constantly, putting him in a constant state of fear and vigilance.

PA Reports that Guide Mental Health Reform

From the Pennsylvania Commission on Crime and Delinquency
The PA Commission on Crime and Delinquency (PCCD) released a report in spring 2007 named The Economic Return on PCCD's Investment in Research-based Programs: A Cost-Benefit Assessment of Delinquency Prevention in Pennsylvania. (http://www.pccd.state.pa.us/pccd/lib/pccd/juvenile/new_website/final_pccd_return_on_investment.pdf)

This research focuses in great part on providing mental health and prevention interventions to youth, and diverting them from the traditional responses which are supposed to change behaviors but which in fact were designed based on hunches and anecdotal at best evidence.

In the report summary, its authors make the following assertion:
"Recently, economists and policy researcher have begun to conduct cost-benefit analyses of prevention and intervention efforts to determine whether to the potential benefits of a variety of strategies justify the funds necessary to implement them. In this report...we examine the return-on-investment for seven research-based programs that are supported by the PCCD and in widespread use throughout Pennsylvania.

Using conservative and widely accepted methodology, we determine that these programs not only pay for themselves, but also represent a potential $317 million return to the Commonwealth in terms of reduced corrections costs, welfare and social services burden, drug and mental health treatment, and increased employment and tax revenue. The programs described in this report produce returns of between $1 and $25 per dollar invested, can generate cost savings as great as $130 million for a single program."

From the PA Legislative Budget and Finance Committee
In 2006, the PA Legislative Budget and Finance Committee (LB&FC) released the findings and recommendations of a yearlong study of the Pennsylvania mental health service systems for children and youth. The report, titled PA's Mental Health System for Children and Youth , was made through extensive interviews with system stakeholders, including families, providers, and state government administrators. The report is available at http://lbfc.legis.state.pa.us/, and clicking on Reports, under the Health and Welfare heading.

Gaps and concerns identified in the report include:

- Services are not currently well integrated.
- State outcome data is lacking.
- Shortage of child psychiatry services needs to be addressed.
- There is a lack of services for transition-age youth and young adults.
- There is a lack of services for co-occurring disorders.
- Educational services in partial hospital programs should be expanded.
- There is a lack of respite care services.
- There is a need for prevention services.
- There is a need for expanded training and current work force shortages.
- There is a need for culturally appropriate services.

Recommendations of the report include:

- The state should develop a strategic plan with priorities for mental health services.
- The governor should create a Children's Mental Health Services Coordinator reporting directly to the Secretaries of Public Welfare, Education, and Health.
- The state should encourage evidence based service development.
- The Department of Public Welfare should strengthen controls to ensure payment is only for delivered services.
- The Juvenile Act should be amended to address issues of confidentiality and self-incrimination.
- The Department of Insurance should explore including evidence based services in the Children's Health Insurance Program.

A National Charge and a State Mission

National Charge
Through the Surgeon General's report and the Presidents New Freedom Commission report, there is a clear charge and mandate to transform what the Commission found to be a "broken" mental health system, both private and public for citizens of this country of all ages. At the national level, the US Substance Abuse and Mental Health Services Administration (SAMSHA) has committed to support states in transforming their behavioral health systems. For children, SAMSHA has provided that transformation impetus through a System of Care Approach, based on over 20 years of community research grants, many of which Pennsylvania has hosted.

"A system of care is a coordinated network of community-based services and supports that are organized to meet the challenges of children and youth with serious mental health needs and their families. Families and youth work in partnership with public and private organizations to design mental health services and supports that are effective, that

build on the strengths of individuals, and that address each person's cultural and linguistic **needs.** A system of care helps children, youth and families function better at home, in school, in the community and throughout life.

Systems of care is not a program — it is a philosophy of how care should be delivered. Systems of Care is an approach to services that recognizes the importance of family, school and community, and seeks to promote the full potential of every child and youth by addressing their physical, emotional, intellectual, cultural and social needs." The SAMSHA Systems of Care mission is "Thriving in the Community." Excerpted from http://systemsofcare.samhsa.gov/

State Mission

Pennsylvania's Office of Mental Health and Substance Abuse Services (OMHSAS) has been responding to the national call to action and the first hand experiences of children and families frustrations with inadequate behavioral health services through a concerted effort to transform them. This effort began in 2002 with the reinstitution of the Children's Bureau, within OMHSAS. The Children's Bureau director and staff have partnered with stakeholders to institute lasting changes, including the creation of the Youth and Family Institute to reform "Wraparound" services.

These changes are responsive not only to the national mandate and stakeholders, but do in effect respond to the many recommendations of the LBFC report. OMHSAS annually creates priorities and plans for transformation. OHMSAS recently implemented an Evidence Based Practice Center process. They have implemented a monitoring system to catch payment fraud. And through the MacArthur Foundation's PA Models for Change Initiative, of which OHMSAS and MHAPA are key leaders, we are working on amending The Juvenile Act to address issues of confidentiality and self-incrimination. *Much work is still needed however to resolve the gaps the report so aptly spotlighted.*

Continuing the Commitment to Transformation for PA's Children, Youth and their Families

The Mental Health Association in PA (MHAPA) works with a network of local family advocates, housed in our affiliates or other community organizations, which provide vitally needed guidance to families and their youth on being effective self-advocates and consumers. Additionally, they provide vitally needed local leadership in systems policy and reform, and oversight of services and programs. By galvanizing community buy-in and support for effective systems, they are able to ensure the front line changes that cannot be dictated from afar by the state and national government. MHAPA supports these front line stakeholders by providing essential information through the monthly online newsletter , PA Children's News, and represents the family and advocacy voice across the child serving systems in Harrisburg.

There is stakeholder consensus on one central point- we must in Pennsylvania have a public health approach to children's mental health. To accomplish this, PA must have a coordinated response based on evidence-based practice, which responds early and effectively to children's needs. **All children have mental health needs, just as all children have physical health needs.**

A Leading Nationally Recognized Approach

The MHAPA has joined with other leading state advocacy groups, as well as the PA Departments of Education and Public Welfare to advance a universal approach to children's mental health resiliency and wellness. Many other states have adopted this approach, some by embedding the reform in legislation. This approach is called School Positive Behavioral Supports and Interventions (SWPBIS). It is housed within the school system, because that is where children live. It is merged with the No Child Left Behind, Academic Standards reform already in place in our schools. SWPBIS is an evidence-based practice, which demonstrates that by addressing the social and emotional needs of students, that there is significant improvement in academic performance, school climate, and reduction in disciplinary problems. **Rather than a program of services, SWPBS is a framework for effectively organizing the current services provided in schools, and training staff in approaches, which promote positive outcomes and decrease negative ones.** From prevention to diversion from high end services including Juvenile Justice placements, SWPBS has revolutionized the way we support and intervene with children. Read School-Wide Positive Behavior Support: A Plan for Pennsylvania at http://www.elc-pa.org/nochild/nochild.html

We ask the Legislature's support in SWPBIS's implementation.

Excerpts- PA Children's News, Oct, 2008 www.pachildrensnews.org

Article- Family Voice in Youth's Treatment Decisions

Editor's Note: This is a brief article from a father in Pennsylvania struggling with the "Age of Consent" law.

During the first meds check after my son turned 14, the Dr. explained to him that he did not have to take his medicine, if he did not want to. He also said he could sign his own waiver denying the meds, and that he could sign his own treatment plan. This made my son very happy. However, none of this was explained to me before it was told to my son.

Within approximately one month of not taking his medications, the following behaviors became very escalated.

1. He refused to go to school. On the days that he did attend school, he would not participate.
2. He became very disrespectful to all people in authority.
3. His behaviors caused much conflict between his mother and myself. Neither of us were able to get him to comply with requests.
4. He felt his way was the only way.
5. His mother and siblings were concern when he was present

Due to his behaviors and actions, he is now waiting to be tried as an adult for criminal charges. All this, and he is only 15 yrs old.

"I am Doing Well According to Who?"

Editor's Note: This is a brief article from a young adult in Pennsylvania who struggled with his right to consent to treatment.

As a young adult, I was on a cocktail of meds and my parents and teachers thought that they were great, and so did I at first. After a while, I gained 15 pounds and lost interest in a lot of my favorite things including sports and girls and all I did was sit around and play on the computer all day. Although I wasn't running amuck the pills only numbed me, they didn't have any lasting therapeutic effect; if you took them away, I would go back to my same old self. I was even on medications for the side effects of my medication! Actually, some pills became a deterrent to bad behavior because of their side effects and were even used as threats and some pills.... well they made me feel good which I latter found out they are the ones that are abused and addictive.

As my medications began to change my behavior, my trips to the therapist faded away, a mere inconvenience when you could take a five-minute drive to the pharmacy. When I finally decided to stop taking my meds, I didn't tell anyone but after a week, everyone knew. My parents were furious and it soon became a matter of principle and their perceived right of parental will to make me take them and on my side I felt that it was my body and I should have the final say. I felt that as long as I wasn't a danger to my self or others, not just a mere inconvenience, I should be able to decide whether or not I wanted meds, therapy or a combination of both. At this point though my parents wouldn't even negotiate, they wanted me on my meds and a therapist was out of the question until I started taking them again

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Looking back, I can say that this was one of the most traumatizing interactions of my life! Something which was supposed to help me hurt me and whether or not I liked it my parents were convinced that it was going to continue. They were convinced that I was not taking them because it had something to do with my diagnosis not the side effects and they were not willing to even negotiate until I started taking them again. Unfortunately, this struggle continued for several years until I was able to learn appropriate coping skills and seek treatment on my own. I am sure that my story is repeated many times every day. Although some of the laws have changed, I still don't think that they grant youth enough power and I am sure that parents feel that their children have too much power. I often wonder if the roles were reversed and during the heat of battle..... if I told my Mom to take a chill pill.....would she have?-

Caring for Every Child's Mental Health

- Every child's mental health is important.
- Many children have mental health problems.
- These problems are real, painful, and can be severe.
- Mental health problems can be recognized and successfully treated.

By working together, caring families and communities can help.

The PA Children's News Site, **www.pachildrensnews.org**, provides information on children's mental health issues in Pennsylvania — advocacy efforts, events, policy, disaster planning. And, it provides insight from families on the frontlines.

The site is a product of the Mental Health Association in Pennsylvania (MHAPA) and its partners across the state. Visit us online for more information and/or to provide news and upcoming events from your area. You can contact us at **866/578-3659** or **info@pachildrensnews.org**.

MHAPA Children's News