



1400 Eye Street NW Suite 450 | Washington DC 20005 | t. 202.657.0670 | f. 202.657.0671 | www.firstfocus.org

May 9, 2023

Senator Ron Wyden
Chairman, Senate Finance Committee
U.S. Senate
Washington, DC 20510

Senator Michael Crapo
Ranking Member, Senate Finance Committee
U.S. Senate
Washington, DC 20150

Dear Chairman Wyden and Ranking Member Crapo,

Thank you for your bipartisan leadership on the Senate Finance Committee regarding mental health issues, particularly for children, youth and young adults. I am writing to you regarding the recent hearing titled “Barriers to Mental Health Care: Improving Provider Directory Accuracy to Reduce the Prevalence of Ghost Networks.”

First Focus on Children is a bipartisan advocacy organization dedicated to making children and families a priority in federal and budget decisions. Since the release of the U.S. Surgeon General’s report on youth mental health in December 2021¹ we have been pleased to see Congress shine a light on the array of major behavioral health system issues that need to be addressed, including network adequacy. We appreciate the invitation to share our thoughts on the issue of “ghost networks” as it impacts children, youth and young adults.

¹ U.S. Surgeon General Issues Advisory on Youth Mental Health Crisis Further Exposed by COVID-19 Pandemic. HHS.com, December 7, 2021. <https://www.hhs.gov/sites/default/files/surgeon-general-youth-mental-health-advisory.pdf>

Mr. Chairman, we agree with the comments you made in your opening statement. “In a moment of national crisis about mental health, with the problems growing at such a rapid rate, the widespread existence of ghost networks is unacceptable.” This Committee is already familiar with the range of issues facing our nation’s youth. The February 15, 2022 hearing, Protecting Youth Mental Health: Part II – Identifying and Addressing Barriers to Care” and the subsequent white paper on mental health and youth² laid out many of the staggering statistics of the increased demand for mental health services among children, teens and young adults. It is widely agreed that while Covid-19 exacerbated the crisis, our teens were in crisis before the pandemic. The current statistics are alarming. Roughly 42% of high school students felt so sad or hopeless almost every day for at least two weeks in a row that they stopped participating in their usual activities.³ One in ten high school students attempted suicide one or more times during the past year.⁴ A statistic that hits at the heart of the ghost network problem, and a statistic that you have noted in previous hearings, is that typically 11 years pass between the onset of symptoms in our children and adolescents and when they first receive treatment.⁵ Nationwide, more than 60% of children who experience a severe depressive episode do not receive treatment.⁶ This is simply unacceptable and we can do better.

While Congress passed and President George W. Bush signed the Mental Health Parity and Equity Act (MHPAEA) into law in 2008 (which addresses the disparities between general and behavioral health care and seeks to create equal access to behavioral health services), millions of children and their families have not enjoyed the benefits of this important law. Insurance companies have skirted the universal benefits guaranteed by the MHPAEA law, and enforcement of the law is lacking, meaning no one, including children and youth, has achieved equitable access over the past 14 years. Even the 2010 passage

²U.S. Senate Finance Committee, Youth Mental Health Discussion Draft. June 15, 2023. <https://www.finance.senate.gov/chairmans-news/wyden-crapo-carper-cassidy-unveil-youth-mental-health-discussion-draft>

³“Youth Risk Behavior Survey Data Summary & Trends Report,” Centers for Disease Control and Prevention, February 2023. https://www.cdc.gov/healthyyouth/data/yrbs/yrbs_data_summary_and_trends.htm

⁴“Youth Risk Behavior Survey Data Summary & Trends Report,” Centers for Disease Control and Prevention, February 2023. https://www.cdc.gov/healthyyouth/data/yrbs/yrbs_data_summary_and_trends.htm

⁵U.S. Surgeon General Issues Advisory on Youth Mental Health Crisis Further Exposed by COVID-19 Pandemic. HHS.com, December 7, 2021. <https://www.hhs.gov/sites/default/files/surgeon-general-youth-mental-health-advisory.pdf>

⁶Youth Ranking 2022. Mental Health America. <https://www.mhanational.org/issues/2022/mental-health-america-youth-data>

of the Affordable Care Act did not force all insurance companies to offer parity in behavioral health services. While patients have the legal right to equal access and coverage of behavioral health treatment services, coverage still remains restrictive.

What a Lack of Parity Means to Children and their Families

When a child or teenager has a behavioral health crisis (mental health issue, eating disorder, substance use disorder, etc.), a parent's first instinct is to seek immediate and appropriate care so their child can receive a timely, proper diagnosis and treatment. In other words, their response is exactly the same as if their teen had just broken their arm in a bike accident or experienced a seizure. Unfortunately, when children and teens experience a behavioral health crisis – even if they are covered by health insurance (private insurance or Medicaid) – help may not be on the way.

For families with health insurance, the lack of adequate networks or the existence of so-called “ghost networks” is a brick wall or a frustrating exercise fraught with emotional turmoil for the child and the entire family. As we heard in your hearing and from many stories in the press, families often encounter outdated or severely limited provider network directories. Some providers are no longer in their network. Or parents are told that the waiting lists are weeks- or months-long. Providers may be so overburdened that they are not accepting new patients. In addition to barriers from ghost directories, insurance companies may impose limits on the number of behavioral health visits a child can have in a calendar year. Families may also have to pay much higher co-pays for behavioral health care visits than for traditional physical health visits.

When children cannot access home and community-based services in real time, they go without proper care and risk experiencing a crisis. They may contemplate suicide or harm someone else. At the point of a true crisis, a hospital emergency room may be the only viable option for the child or teen to receive immediate care – a route into the system that is traumatic for the child and family, chaotic, and costly. Sometimes, even emergency room care for behavioral health issues requires prior authorization before hospital treatment which can result in several days of delay – yet another barrier to care. Ideally, children and youth should receive care in the early stages when symptoms first appear so that they never have to experience a crisis.

Solutions

Solving the multifaceted problem of achieving parity will require government, providers, group health plans, states, and other entities to work better together. Congress and the relevant agencies must strengthen and enforce the existing 2008 MHPAEA law, and must provide states with adequate support to oversee, monitor, and enforce parity at the state level. First Focus on Children supports lifting the voices of children and youth and

empowering parents who face barriers in finding and paying for care for their children. Efforts to investigate consumer complaints about denials of services and/or network adequacy issues are important to children and families.

Our ability to address the youth mental health crisis in this country hinges in part upon parity. Achieving parity will require:

- network adequacy
- a diverse and increased number of workforce professionals and non-professionals
- fair reimbursement rates
- consumer empowerment and education
- better oversight and enforcement of insurance companies.

We agree with Chairman Wyden on a three-pronged approach of oversight, greater transparency and enforcement to ensure these network directories are more accurate and reliable for consumers. Only when our nation's children and youth can access affordable, high-quality behavioral health services in a timely fashion — a standard we apply to the rest of their health care — will we reduce their rates of anxiety, depression, suicide, and substance use and offer them a brighter, healthier future.

Thank you for your leadership on mental health issues and for your commitment to ensuring the good health and well-being of all children. First Focus on Children looks forward to working with you and your staff. Please feel free to contact me at BruceL@firstfocus.org, or Elaine Dalpiaz at ElaineD@firstfocus.org, or Averil Pakulis at AverilP@firstfocus.org with any questions.

Sincerely,



Bruce Lesley
President, First Focus on Children