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Lifting Youth and Family Voices to Transform the Children's Behavioral Health System

Advancing Meaningful, Actionable Change to Promote Equity and Innovations in Mental Health and Substance Use Care Delivery

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INTRODUCTION

"Lifting Voices," a comprehensive project with three phases, was established to advance equity and innovations in child and youth behavioral health policy and care delivery. Heidi Arthur, Ellen Breslin, and Sheilah Gauch initiated Phase 1 of this project in June 2023.

We are parents of children who nearly died on multiple occasions from severe behavioral health conditions, and we are professionals with a deep understanding of the opportunities and challenges faced by behavioral health care policy makers and reformers. Thankfully, our children are in recovery and unlikely to face an uncertain future in our nation's complex care delivery system. Our children are also collaborators in this project, joined by other "parent-professionals" and their children recruited from our respective networks to inform Lifting Voices. Phase 1 as described in this brief.

We know that **treatment works, and recovery is possible**. Lifting Voices seeks to optimize our unique and vital vantage at this major inflection point in history when every state is investing in reforms to end the nation's growing youth behavioral health crisis. In our professional roles, we advise organizations on policy, programmatic, and practice transformation. We recognize a more pressing need, however, to advocate for meaningful and actionable changes to create a system of care for youth.

Together, we found a common purpose in our shared belief that our knowledge, desperation, and resources afforded us access to interventions that should be accessible to every youth who needs them. Our experience of the care delivery system also made it clear that we must highlight urgent improvements necessary to support struggling children and parents.

The authors will present Phase 1 findings at Putting Care at the Center, the annual conference of the Camden Coalition's National Center for Complex Health and Social Needs Initiative. See: *Putting Care at the Center 2023*, Elevating behavioral health in whole-person care. Boston, MA, November 1-3, 2023.

Authors:

Heidi Arthur, LMSW, has over 25 years of experience in delivery system redesign to promote health equity and build access to community-based health and human services. She specializes in supporting national, state, and local leaders to finance, design, and implement interventions that promote child welfare, maternal health, and child and family mental wellbeing. Her child, now age 16, was in treatment from the age of 8 for anxiety but was also suffering from undiagnosed major depression that was not evident until suicidality, and several serious attempts, led to residential treatment and then access to Dialectical Behavioral Therapy, which has proven critical to recovery.

Ellen Breslin, MPP, is a health policy and financing expert, serving national, state, and local clients. Her career spans over 35 years, holding various key roles at the Massachusetts State House, the Congressional Budget Office, and MassHealth. She has dedicated her career to advancing justice for individuals with chronic conditions and disabilities. Her son has a mental health condition with a substance use condition. He was diagnosed at a very young age with hyperactive and impulsive type attention deficit hyperactivity disorder (ADHD). In response, she sought out the right services, the right

educational environment, and sports to support his needs. During high school, he moved in a new direction, from vaping to marijuana to benzodiazepines. Traditional treatments did not work. His life fell apart: his grades plummeted, he abandoned sports, and he lost his part-time job. High school administrators dismissed the seriousness of this new trajectory. His parents arranged for him to attend a three-month wilderness program for outdoor behavioral health care, followed by a thirteen-month therapeutic boarding school for a blend of individual and group therapy alongside academic support to facilitate his recovery in personal growth and regain control of his future. Both programs were located on the other side of the country. He is a recent survivor of two fentanyl overdoses and practices harm reduction approaches. Her son is 21 years old and in college.

Sheilah M. Gauch, LISW, M.Ed., is the Principal and Clinical Director of Dearborn Academy, a therapeutic day school that serves students with social/emotional and learning needs. She is also a Licensed Independent Clinical Social Worker and educator with over 20 years of experience working with and advocating for students with complicated mental health needs. In addition to her work with students, Sheilah engages with caregivers, districts, and mental health professionals through consultation, training, and public speaking. Sheilah has two of her own children, whose significant mental health issues appeared treatment resistant. They presented with obsessive compulsive disorder (OCD), separation anxiety, panic disorder, mood lability, sensory issues, sleep disturbance, and suicidality. When another mother shared information about Pediatric Acute-onset Neuropsychiatric Syndrome/Pediatric Autoimmune Neuropsychiatric Disorders Associated with Strep (PANS/PANDAS), Sheilah was entirely unfamiliar with this condition. However, given the severity of her children's illnesses, she had genuine concerns about the risk of suicide and, as a result, chose to consult her pediatrician to investigate the possibility and exclude it as a potential cause. Thankfully, her pediatrician knew of the illness, willingly screened them, and subsequently treated them successfully. Both children began to heal in ways that were both shocking and unexpected. Their OCD and acute suicidality abated quickly, and they were able to return to their community schools after years spent in therapeutic settings. They are both now thriving in their respective colleges. Sheilah has spent the years since their diagnoses learning and teaching others about PANS/PANDAS. She co-led the creation of the Massachusetts Coalition for PANS/PANDAS legislation which successfully championed the passage of both an insurance mandate for the sickest children with this illness in the Commonwealth as well as established a department of public health (DPH) PANS/PANDAS Advisory Council, where she serves as the co-chair. Sheilah received the 2020 Commonwealth Heroine Award for her work on the Massachusetts PANS/PANDAS legislation as well as her leadership as the Chair of her local Special Education Parent Advisory Council.

The authors would like to thank their children and all the participants who agreed to share their time and their experiences to help other young people and their families. We also thank HMA's Raisa Alam, MPH, who donated significant time to supporting our survey.

NATIONAL YOUTH BEHAVIORAL HEALTH CRISIS

Our nation's children and youth are experiencing a profound behavioral health crisis, and our current behavioral health system requires significant improvements to meet the demand and staunch the surge.

According to national survey data, one-third of high school students and half of respondents who are female report feelings of sadness or hopelessness.[1] Pediatric mental health hospitalizations have skyrocketed due to attempted suicide, suicidal ideation, or self-injury diagnoses, which have more than doubled during the past decade.[2] Rates of drug use have increased among younger students, with more than 20 percent of eighth graders and nearly half of high school seniors (46.6%) reporting illicit drug use at least once during the four years prior to the pandemic's impact in 2020.[3]

The Centers for Disease Control and Prevention (CDC), the American Academy of Pediatrics, and major medical journals have sounded the alarm. In 2021, the American Academy of Pediatrics declared that youth mental health is a national crisis[4], and the U.S. Surgeon General issued a formal public health advisory.[5] Suicide is now the second leading cause of death for children ages 10−24.[6] Overdose death rates have increased 500 percent since 1999 among teens and young adults ages 15−24.[7]

Despite this crisis, it is estimated that eight in 10 children and youth who have behavioral health needs do not receive the care they need.[8]

Purpose

We seek to identify and elevate policy, program, and practice changes that respond to the needs of families and their youth who have complex behavioral health care needs. We are professionals with a deep understanding of the opportunities and challenges inherent in delivery system transformation. Our children, youth, and young adults with complex behavioral health needs have traveled a long and painful road. They have been both harmed and helped by the current behavioral health system. They have also received significant help from sources of care which are not widely available to most youth. We feel an imperative to share our lived experience and lift the voices of other families and youth to create meaningful change in the youth system of care to keep them alive and help them thrive.

Our purpose is to:

- Unite around our experiences as parents, professionals, and youth and young adults in recovery.
- Elevate the experience of others who share our expertise and lived experience.
- Expand access to effective best practices that prevent mental illness and improve the early identification and treatment of child and youth behavioral health conditions.
- Advance equity, parity, and innovations to promote recovery for children, youth, and young adults with mental health and substance use conditions.

Three Phases

From June to September 2023, we conducted Phase 1 of our project to find common ground among the experiences of other parents and their children with lived experience and expertise. We will share our Phase 1 findings via a poster session at Putting Care at the Center, the annual conference of the Camden Coalition's National Center for Complex Health and Social Needs Initiative.

See: *Putting Care at the Center 2023*, Elevating behavioral health in whole-person care. Boston, MA, November 1-3, 2023.

We aim to secure funding to launch Phase 2 by January 2024. We plan to sharpen our focus in alignment with complementary efforts underway by other groups and input from national leaders. We would also like to engage a far larger sample of parents and youth. We plan to explore the key focus areas identified in Phase 1, with a more diverse sample of parents and youth, taking into consideration family income; coverage; geography; race, ethnicity, language, and disability (RELD); sexual orientation and gender identity and expression (SOGIE); and education.

In Phase 3, we plan to create actionable change by leveraging what we learn to make an impact in national, state, and local policies, programs, and practices.

PHASE 1

Methodology

In Phase 1, we recruited 19 participants including 12 parent/caregivers and 7 of their children, youth, and young adults with lived experience of mental health and substance use disorder. Participants completed separate surveys and attended a focus group convened separately between adults and youth.

Parent caregivers included professional clinicians, health policy advisors, behavioral health advocates, and school educators from our personal and professional networks. Parent professionals included 6 clinicians (1 psychotherapist and 5 social workers), 2 health policy experts including two former Medicaid officials, and 2 educators. The parent sample included 6 parents between 40-50 years of age and 6 parents over age 50. They are caregivers to youth and young adults with complex mental health and substance use disorder conditions. The youth sample included one youth (15 years old) and six young adults (20 or 21 years old) with lengthy histories of engagement with the behavioral health system.

Survey Questions for Parents and Youth

Parent/Caregiver

1. When did you first identify that your child required any kind of special intervention?
2. For what specific needs did you first seek care?
3. Was your child able to receive appropriate intervention? Did you face barriers to getting appropriate care? What were the gaps in the system? Please describe those.
4. Please list the interventions your child has received, indicating the ages and the setting. (Settings: school, community program, private/public clinic, individual clinician, hospital, residential facility, or other types of settings).
5. Please describe what has been the most effective care your child has received and the main elements of the care that “worked” for your child or family, and please describe your feelings, as a parent or caregiver, about your experience with your child’s most effective care givers?

6. Please describe what has been the least effective about the care your child has received, and describe your feelings, as a parent or caregiver, about your experience with your child's least effective care givers?
7. Can give us a list of the three most important changes that you would like to make to help others and to address the barriers and gaps? What is the change? What problem or gap does this solve?
8. How much support do you receive from an advocacy organization, legal support, spiritual/ faith-based, community aid, or another organization? Please describe.

Youth

1. Please give us an idea about your learning, attention, behavior, and mental health and/or substance use challenges.
2. What was your journey like to getting the care you needed?
3. What was the best part of this journey and why? Who or what worked?
4. What was the worst part of this journey and why? Who or what did not work?
5. Can give us a list of the three most important changes that you would like to make to help others? How do we solve the problems in the system? What is the change? What problem does this solve?
6. How much support do you receive from an advocacy organization, legal support, spiritual/ faith-based, community aid, or another organization? Please describe.

Key Insights

1. Parents (caregivers) with lived experience navigating the behavioral health system for their children reported significant investment and personal impact.

- Parents reported that finding the right care took at least a decade, and most (10 of the 12 parents) reported that more than 10 years was necessary to seek the right care for their children. Some parents reported more than 17 years of experience navigating the system.
- Parents reported significant financial and personal impacts. About 50 percent of parents reported a 25-50 percent reduction in employment.
- All parents had private insurance but experienced a high financial impact: 5 parents reported that insurance covered between 50-70% of their child's care, while other parents reported that insurance covered as little as 10% of care (2 parents) or no coverage for outpatient care (1 parent). A few parents reported insurance covered 25% of their children care (3 parents).
- Parents reported significant out-of-pocket costs, ranging from $15,000 to well over $250,000.
- Parents also reported significant negative impacts on their own mental health and relationships, including feelings of loneliness or being judged by providers as they feared for their children's lives, and limited support from community resources.

2. Parents and their children want to “throw out the code book” or expand the code book to provide youth with coverage that supports person-centered, whole-person care.

- Many parents found that traditional insurance does not cover what youth and young adults need.
- Parents described paying for services not covered under health insurance. This included outpatient Dialectical Behavioral Therapy (DBT) and activity-based residential programs such as wilderness programs.

3. Parents and young adults indicate that finding what works is an exceptionally long and painful journey.

- Families reported long and painful journeys, ranging from 10-17 years. These journeys are also on-going.
- Parents reported identifying that their child required special interventions as early as 3 years old. The average age for first identifying special needs was 8 years old.
- Some journeys or about half of the parents reported at least 8 major interventions involving therapy, inpatient and residential admissions, outside school district placements, and wilderness programs. Some reported as many as 12 major interventions.
- Parents universally reported feeling judged, blamed, and frightened that their children were going to die without getting the right care.
- Youth universally reported feeling as though their care was not individualized and complained of the same interventions/medications being used repeatedly, even when it was apparent it wasn’t working. Youth experienced harm and frustration in the rigid, inflexible system.
- Common themes include delayed diagnosis, multiple providers, repeated inpatient, and residential admissions.
- Parents, especially of children over age 18, feel isolated and vulnerable to the system, which stops communicating with them when teens turn 18.
- Youth want mental health education to start in elementary and middle school so kids can understand their experience and get help, as they would have with any medical need.
- Traumatic experiences in inpatient and residential settings compounded behavioral health challenges, delayed recovery, and demand scrutiny and action.
- Youth want earlier education and the right intervention earlier on from better trained providers who treat the person and personalize care via more creative and engaging options.

4. The (right) treatment does work and recovery is possible.

- Resources, persistence (for several youth, 15-20 assessments and interventions were necessary), knowledge of the system, and the right intervention can lead to recovery from even very severe illness.
- When properly treated and with supports, some children and youth with very complex conditions attend college and seek employment.
- Three out of five young adults would like to join the behavioral health workforce.

The next section summarizes the group’s shared imperatives, illustrated by quotes from the participating parents and youth.

Today's children and youth who have complex mental health and substance use conditions are tomorrow's adults with complex care needs, if they survive…

FIVE IMPERATIVES

Five imperatives for change emerged from our small, unique sample of parent-professionals and their youth/young adults. The group converged around the need to:

1) **Raise awareness** about the prevalence and impact of mental health and substance use among children, parents/caregivers, and professionals in order to intervene early and with the right care.
2) **Reduce stigma**, including the persistent bias within the behavioral health system which delays access to the right care and limits supports available to parents and children.
3) **Expand access to screening and intervention**, particularly in schools and pediatric settings.
4) **Improve the quality of care**, which is spotty at best; youth raised particular concerns about safety within inpatient and residential settings.
5) **Provide person and family-centered, whole-person care**. Parents and youth reported that behavioral health care options are extremely limited and rigid; families are rarely supported.

The following quotes from youth and parents illustrate each of these imperatives:

#1 - Raise Awareness

YOUTH

- **"13-year-olds are not equipped to handle the kinds of hard conversations about safety and mental health that are happening in friend groups** … I knew that an adult needed to know, and it felt overbearing on me to know … I felt like I needed to tell someone."
- "I have all these resources … therapy and communicative parents, but I'm surrounded by friends whose parents don't even believe in anxiety … **for them, school is their safe place, but the resources aren't there**. They turn to their friends."
- "**I was in middle school and had nowhere to go for help**, had first OCD symptoms and didn't know what was going on. I wasn't able to get help until my sophomore year of high school."

PARENT

- "My son's addiction started with vaping in high school. **The school system told me I was over-reacting.** My son's addiction worsened in high school. His pediatrician gave me some numbers to call." (Son overdosed twice at age 19.)
- "**Ensure a differential diagnosis of ruling out medical is truly done every time a mental health condition is diagnosed.** Maybe if this had been done, he would have been caught sooner." (Child was diagnosed with PANS/PANDAS after years of misdiagnosis.)

#2 - Reduce Stigma

YOUTH

- "There's complete stigma over conversations that we need to have. **Kids are trapped in a cycle of not knowing how to ask for help – and not having people to ask**."
- "I don't know why they call it mental health and substance use; it is all mental health."

PARENT

- **"Clinicians are trained to see the parents as causing/enabling issues … we love our kids. They have a health condition."**
- "When I think about ways adults in schools have handled things with my child, I feel incredibly angry and resentful … I hate being on the receiving end of what feels like so much judgment and child and parent blaming."
- "They could only see him through the lens of a behavioral problem. They kept him in daily 5-point restraints … **It was very clear to us that people did not like him and could not see any good in him**. I spent so much time trying to show them he was a very ill child and not in control - trying to engender some empathy so they wouldn't hurt him. It was terrifying and I couldn't help him - nothing was helping him."

#3 - Expand Access

YOUTH

- **"Even with IEP and 504, the school-based services are not adequate."**
- "Unless you already were connected in the system and had an IEP or a 504 or had the adult who could jump through those hoops, then **it was hard to connect with services**. The school psychologist only reserved for those who were connected for services already and the Counselor was focused on college readiness and not MH crisis."
- "Friends say counselors can't be trusted – they'll tell your parents; they'll call the police. There's a threat of child services being involved. Concerns about ICE, deportation … it was crazy. Mandated reporters make it hard to trust anyone—we need to be told what our rights are when we are working with them. **The boundaries aren't clear. Hard to trust the boundaries that people perceive, it's so subjective and about that person's judgment about something that maybe wasn't a threat and was perceived as a threat."**

PARENT

- "In our daughter's case, because there were no small group classes in our public school, **she had to leave her community school**. This was devastating, shameful, and profoundly hard for the whole family. We were no longer able to feel we were part of our community and loss critical connections that may have offered support."
- "He was not regaining any sort of health, and his mental illness was only increasing in severity no matter what we did. No psychotropic medication was working, no therapeutic intervention, no amount of state support (DMH, police, crisis teams) was changing his symptoms. **The only thing that shifted his acute suicidality and rage was treatment for PANS/PANDAS.** We needed to use a different treatment to heal his body to begin to heal his brain."
- **"Eating disorders and self-injury or suicidality and eating disorder, many places would not take my child if both were concerns."**

#4 - Improve Quality

YOUTH

- "I was both chemically and mechanically restrained multiple times for simply being annoying and I just got worse and worse…. **It was a common occurrence that staff would sit and watch as people were becoming distressed and escalating and wait for it to warrant restraint** because the only thing they knew how to do was restrain. It wasn't their fault that they had received no training in how to interact with people in distress or how to mediate and deescalate crises, but the result was that situations that didn't need to escalate to the point of restraint would simply because that was the only time the staff knew how to intervene."
- "Experience based therapy … solves the problem of boredom in treatment."
- **"(Program policies) went with what was easiest thing and not what was the best thing for me**…when I couldn't stop running in the halls, they took away my outside time for 2 months, then took away the puzzles I did every day … these consequences were not related to the action and were not helpful".
- "It is a broken system. I felt complete dehumanization. Basic human rights … like how to be treated like a deserving person is fundamental to improvement."

PARENT

- **"My child tells horror stories, not so much about their own experience, but about what they observed happening to other children** - particularly children who don't have involved and educated parents as advocates."
- "I consider the time my son spent sitting on the psychiatrist's couch a complete waste of time. The psychiatrist's approach was parent-centric, not child-centric and the provider was not an addiction specialist."
- **"We need to start listening to (and funding) people looking for root - and treatable – causes** … I hope I live long enough to see so-called "alternative" medicine make its impact on the mental health and wellbeing of people, especially children."

#5 - Advance Person-Centered, Whole-Person Care

YOUTH

- **"Treat the person, not the illness."**
- **"The inpatient program was not personalized for me—they were making jump decisions without me being fully part of the conversation … you lose control of your own healthcare.** But you go there because you feel scared and out of control and it takes more of that from you. You've completely lost yourself and someone is telling you who you are."
- "Minors with mental health challenges have compounded vulnerability: they are minors, away from guardians, they have mental health challenges …. the people who are aware of these vulnerabilities need to actively fight against these vulnerabilities. **The people who interact with us day to day in these places have no skills in MH and see us as a chore. It feels like it's about power."**
- **"There needs to be a balance** … even in places where they do ask what you want … they were so gung-ho about being patient-driven that they wouldn't do anything until I asked for what I needed, and I told them I couldn't ask for that. We shouldn't have to be the experts on MH should only have to be the experts on ourselves."

INNOVATIONS

In response to the question asked about the change respondents want to see in the children's behavioral health system, we received many solutions. The information in the following tables reflect our "raw notes" from parent and youth survey responses.

Parent/Caregivers

Parents	What is the most important change? What problem or gap does this solve?
1	• Providing education to schools, helping teachers, athletic coaches, parents, and providers understand what rock bottom looks like. • Expanding insurance coverage to address all needs and throwing away the code book to spark innovation and fill in care gaps. • Covering programs that allow children/teens to shine, to build confidence and in any format - like hiking, etc.
2	• Availability of quality providers that take insurance. • Staffing and training in hospital settings. • Make it easier for people to find care.
3	• Ensure a differential diagnosis of ruling out medical is done every time a mental health condition is diagnosed. • Ensure staff in more restrictive settings (hospital, school) have sufficient professional development and training. • Change the narrative in communities to reach out and offer support and services, break the stigma.
4	• Standardize that mental health professionals will use existing diagnostic screening tools when diagnosing, not just intuitive feelings and guesses. Critical medical rule outs, DSM 5 differential diagnosis. • Once a diagnosis is obtained, to use empirically backed, data driven clinical interventions. • Ensure all children have access to the least restrictive setting for school.
5	• There needs to be a consistent approach for all payouts and mental health clinicians need to accept insurance. • There is a great need for more mental health clinicians.

Parents	What is the most important change? What problem or gap does this solve?
6	• Pediatric BH integration: screening, brief intervention, medication prescribing/management, consultation/coordination with specialist; addresses access barriers and would help get to the right intervention sooner. • School-based Orton Gillingham services. • School-based mental health education using DBT skills, school and community-based DBT for intervention, and improved provider and school participation in care coordination.

Youth

Youth	What is the most important change? What problem or gap does this solve?
1	• Train direct care staff. Staff were not trained and did not know how to interact with people in distress. • Change the daily schedule of hospitals; provides therapeutic and non-therapeutic benefit, people get bored and agitated, must have a certain number of hours of engagement each week. • Allow harm reduction techniques, in a safe way; allows people to achieve the sensations in a safe way.
2	• Test for neurological. • Provide more resources to be able to stay in district. • Provide more social supports for those placed out of district.
3	• Provide experience-based therapy. • Do more patient history to treat the person not the illness.
4	• Educate people about mental illness, b/c many people in health care do not know mental health. • Ensure that people have care lined up before they leave the hospital. • Ensure more public resources to respond to people in crisis.
5	• Personalize help. • Provide DBT in school curriculum. • Make mental health more available, including in-home supports more readily accessible.

LOOKING FORWARD: PHASE 2 BROADER ENGAGEMENT

Engaging a Diverse Sample of Parent Caregivers and Youth

Proposed Focus Areas for Phase 2

We want to explore equity issues for children and youth with complex needs, whose families lack the resources to pay out of pocket but must reduce their employment nonetheless in order to meet their care needs.

- Equity across payers (Medicaid vs. commercial).
- Parity between medical and behavioral health coverage across payers.
- Alignment between coverage for mental health and substance use conditions and what parents and youth and young adults want from their insurer.

We want to lift voices from a more diverse array of parents and youth and young adults across RELD, education, profession, insurance, and geography to share their BH care experiences.

- Range of care experiences from parents, caregivers, and youth.
- Use of best practices across the traditional continuum of school and community resources as well as outpatient, inpatient, and residential systems.
- Range and use of non-traditional care such as wilderness therapy programs.

We want to advance innovative ideas for system improvements related to prevention, early intervention, and quality of care.

- School-based Dialectical Behavioral Skills Training, access to DBT, and improved access to early services for learning and attentional disorders.
- Approaches to early pediatric screening, assessment, and diagnosis (including for learning challenges and neurological disorders such as PANS/PANDA).
- Effective trauma-informed models for inpatient and residential treatment settings.
- De-escalation training and methods to ending Restraints and Holds.
- Youth-endorsed engagement methods and models that are effective, such as outdoor therapeutic programs and experience-based programs, and youth peer support.

We want to engage policymakers, health plans, providers, community-based organizations, and communities to combat stigma.

- Strategies to end stigma to ensure that our children, youth, and young adults receive access to the care that they need and communities support families.
- Targeted strategies to end the stigma around substance use disorder.

RESOURCES

Dialectical Behavioral Therapy Skills Training for Emotional Problem Solving for Adolescents (DBT STEPS-A)

Webinar replay

This webinar presents the Dialectical Behavioral Therapy (DBT) STEPS for Adolescents model, which is a low cost, high impact approach to school-based mental health training for students which empowers schools to intervene and support well-being and resiliency before students are in crisis, self-harming, or suicidal. Attendees learned how to fund and implement this approach to promoting mental wellness as a strategy to reduce the burden on clinical resources designed to treat mental illness. Featured speakers include the curriculum developers: James J. Mazza, Ph.D., Co-Developer for DBT Steps-A and Professor School Psychology Program, University of Washington and Elizabeth Dexter Mazza, Psy.D., Co-Developer for DBT Steps-A and President at DBT in Schools, LLC

Here is a blog post describing DBT STEPS-A within a multi-systemic approach to school-based mental health.

Articles for Caregivers

Sheilah Gauch writes a blog for Psychology Today. Her posts relate to caregiver support, found here:

Whole Child Blog: https://www.psychologytoday.com/intl/blog/the-whole-child

About PANS PANDAS

Here is a compilation of material related to PANS/PANDAS that Sheilah shares with those who believe their child's treatment resistant condition may be related to this often overlooked, strep-related medical diagnosis:

PANS_PANDAS Resource List10-3-23.

- Video from the 2022 Alex Manfull Symposium: https://vimeo.com/789274082
- Webinar – Sheilah Gauch – Understanding and Managing Caregiver Trauma Associated with PANS PANDAS: https://aspire.care/videos/webinar-sheilah-gauch-understanding-and-managing-caregiver-trauma-associated-with-pans-pandas/

About Wilderness Programs

- Here is an example: https://deschuteswildernesstherapy.com/

About Therapeutic Boarding Schools

- Here is an example: https://therapeuticboardingschools.org/montana/montana-academy/

Youth Participant Thesis

An Introspection on the Public Policy of Inpatient Mental Health Care for Children and Adolescents

Lifting Voices Youth Participant Echo Lustig wrote their undergraduate college thesis for Hampshire College on the topic of their personal experience of the inpatient mental health care delivery system. They never thought anyone would read about their experience, much less make changes based on their recommendations. Please alert us if reading this thesis leads to changes in an institution as we would like them to know their experience and their voice matters. Echo Lustig is also available to advise, can be reached via HMA, and will be a co-presenter of Phase 1 findings via a poster session at Putting Care at the Center, the annual conference of the Camden Coalition's National Center for Complex Health and Social Needs Initiative. See: *Putting Care at the Center 2023*, Elevating behavioral health in whole-person care. Boston, MA, November 1-3, 2023.

Echo Lustig Thesis.docx.pdf

ENDNOTES

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