Children and Youth Behavioral Health Work Group (CYBHWG)

May 15, 2025

Watch on TVW

State and Federal Updates

See TVW recording (24:47)

State Updates

- This was a hard legislative session, with very few areas receiving new funding and most areas receiving funding cuts.
    - Early Childhood Education and Assistance Program (ECEAP) eliminated from state budget
    - Infant and Childhood MH was reduced by 50%
    - ECEAP complex needs funds were reduced
    - HB 1272 Children in Crisis-Child and Youth Multisystem Care Project Director Extension passed.
    - Community Health Worker (CHW) rates did not receive new or decreased funding, although a new billing code was counted in Medicaid rate coverage.

Federal Updates

- There are major changes to Medicaid that may put some eligibility categories at risk. Some categories may include:
    - Immigrant health programs for children, adults and pregnant individuals.
    - The concern is when you look at all the policy changes, it appears that it would have a serious impact on who is eligible.

Review objectives and processes for 2025

See TVW recording (51:40)

Highlights

- The team is collaborating with, and hearing from, the CYBHWG and Subgroup Leads to gather feedback and new learnings in order to inform the WA Thriving (Prenatal through 25 Strategic Plan) work.
- Philanthropic support has been secured for strategic communications, with the understanding that the content will come from the CYBHWG and Subgroup Leads feedback and new learning along with everything the team has heard.
- The communication work will start next week with the plan to continue this work even after the strategic plan is presented to the legislature in November 2025.
- There is an intentional overlap and integration between WA Thriving and the CYBHWG to integrate concrete ideas so that they're complementary and not contradictory
- Open office hours have been scheduled to support collaboration in this work.
- Recommendation structure and range of recommendation detail includes

  - The aggregation of each recommendation
  - The rational for each recommendation
  - The alignment for each recommendation with current practices
  - How can we leverage existing assets
  - What are the options for implementation
  - What is the strategic starting point
  - How will the recommendation be financed or funded
  - What determines success
- Recommendation 1B: a unified, layered governance framework that enables coordination by setting clear expectations for working together. This recommendation emerged from multiple feedback sources.
  - Asked how/what is needed to make the most effective use of shared resources going forward.
    - Standardized metrics and methodologies
    - Clarity about what decisions are being made and by whom
    - Integrated data systems
    - Joint planning and budgeting processes across agencies
    - Coordinated implementation for regional and local entities
    - Explicit protocols for managing cross-system cases and service transitions

Resources

- About WA Thriving
- WA Thriving Events

WA Thriving group discussion

See TVW recording (1:55:40)

Highlights

- The team used the Menti program as a tool during the group discussion to rate and discuss the Six proposed components of the coordinated framework in terms of degree of impact and feasibility.
- The Strategic Plan structure was shared with the group to show identified sections of the draft plan.

Comments and Q/A

- The visioning of the past two years is for WA thriving to show a central cohesion and a desire for regionalization and decision-making.
- There has been a lot of dialogue around the connections between state coordination and federal guidelines; there is a disconnect, people may get one thing from a state agency but then not another due to things like waivers, etc.
  - Similar to 988 work, a need to make sure that all the regional partners are working together
- It's important to coordinate not only resources, but care.

- How do we build guardrails so that these ideas can be realized, making sure we trust who is using the data.
- Every time we have to share data, families say it's intrusive. Behavioral Health Providers spend 2-3 hours doing intakes and they don't know where all the data goes, or if it is being used.
- Administrative burden is a large concern, it has people doing the work really overwhelmed, since administrative tasks are not what folks in the field went to grad school to do.
- Standardizing terminology can go a long way.
- We use different data to talk about the same thing, comparing apples to oranges.
- The requirements to protect the data we collect is challenging.
    - What if we prioritized so that collecting data wasn't redundantly extractive?
    - There is data around abortion with really strong protections; this may be a good model to reference.
    - OSPI is a good model too with FERPA.
- It would be helpful to standardize terminology around outcomes, not process measures.
- Communities want data, so different agencies have dashboards that they develop for communities.
    - Some things might be more feasible to integrate rather than client data.
- There is work being done on the standardization of data within 988 crisis care system, a lofty goal of one crisis data system, but there might be something in that work that could be helpful or foundational.
- Often, it's not known what data to ask for, which puts families in a position to go through a longer intake process than they need to.
- Updated protocols for how agencies work together is needed.
- There is lots of focus and conversations taking place around the coordination among systems.
- The WA Thriving work presents a good opportunity to ask why we need this data and what we do with the data.
- Common values across agencies would be to share goals; we can only measure success if we do that.

Public comment

See TVW recording (2:28:30)

Hello, My name is Michelle Whitehead, I am a parent caregiver of a child who is neurodivergent whose diagnosis also intersects with mental health.

I am a constituent of Lisa Callan's 5th Legislative district, and I cannot thank her enough for her leadership in Behavioral Health in Washington State.
My public comment today is from my lived experience. My 12-year-old daughter has a very complex autism profile and requires someone with her at all times. She should not and cannot be left alone.
She can be very sweet one moment and the next go into extreme rage or have self-harm and self-injury episodes. These behaviors didn't happen overnight, but the warning signs were there now when I look with 20/20 hindsight. My daughter has experienced incredible ableism, stigma, judgement, and chronic misunderstanding of Autism, and Attention-Deficit/Hyperactivity Disorder (ADHD), which caused episodes of restraint & isolation, educational neglect, along with mental health neglect from the schools we attended throughout her 8 years of school with transitioning to 9 different schools. Some of her most recent diagnoses that most closely match her profile, and trainings available were never ever mentioned by providers who should have known about them.

Notes

The numerous times CPS was called they should have had targeted resources specifically for my daughter's behaviors, but they had none to offer. No menu of options, choices, or programs they offered until they finally responded to my personal request for services in March of 2024, but it took until May of 2024 when it was too late, my daughter was then taken by a family member with zero understanding, training, or knowledge of anything relating to her special education or caregiving needs. I sought jobs based on the insurance the company had, not based on what the job description said. Imagine doing a reverse job look up and willing to work in any field because insurance was needed most. Even once I got better insurance and went to the premium top tier of care in the Autism community we lost trust very quickly due to the providers inadequate care with medication management, decisions making processes, my daughter not responding to Applied Behavior Analysis (ABA) therapy, and the staff of the organization taking a photo of my daughter at age 6 without her shirt on during an escalation and snap chatted it to another employee and was mocking her. We live in a behavioral health desert in Issaquah. We have spent years on ABA waiting lists because we had Medicaid. There is literally one behavioral health organization who accepts Medicaid Apple Health in Issaquah.

The inappropriate treatment plans we received from providers who did not know how to curb her behaviors were years long, arduous, sucked all my time, energy, resources and many times I left the workforce with good jobs and benefits to be a stay at home to caregiver for my daughter full time and fight these systems who were not appropriately serving her.
How I can be most impactful today is to tell you what we didn't receive.

We didn't receive Wise/Wraparound services from providers who were well seasoned, trained, and well versed in the vernacular of Autism, ADHD, and all its complexities.
Instead, we got practicum students who could not communicate well and did not provide me with access to her treatment plan, take data, and show me what is working and what isn't.

I didn't hear of Pathological Demand Avoidance from any provider which most closely describes my daughter's behavior, I heard from a parent

I didn't ever hear of Rejection Sensitive Dysphoria which came from a provider in an unrelated field of eating disorders

I did not ever hear of masking until other parents told me about it

I didn't ever hear of the term Interoception which came from other parents

I didn't ever hear from any provider of the nervous system, the polyvagal theory, the neuroscience behind her behaviors, and the brain science behind the overactive amygdala from any provider, it came from parents
I didn't ever hear about how to become a low demand parent until it came from other parents

I didn't ever hear from any provider to go see a neurologist, it came from other parents

I didn't ever hear from any provider to sign up for services with the (University of Washington) UW Autism Center

I didn't ever hear from any provider to learn how to co-regulate with my child

I didn't ever hear from any provider to use declarative language

I didn't ever hear from any provider to take suicide classes, learn the warning signs of Autism and Suicide and how to talk to my young child about self-harm. Not ever once.
I didn't ever hear from any provider about Assertive Community Tratment (ACT) which is Acceptance and Commitment Therapy

I didn't ever hear from any provider about neuro affirming care or Trauma informed Care, or Trauma informed response, Or Trauma Informed Approach

Notes

We did not get intensive critical crisis support from any provider longer than 4 weeks which was Children's Crisis Outreach Response System (COORS) with the YMCA
The hours we got from Wise/Wraparound with my daughter was two hours a week.
We did not ever get extensive training or resources around ADHD, which is not just being fidgety, not being focused, and needing to run off our energy. It is so, so, so, much more involved and complex.
We never had any providers specializing in ADHD and executive functioning coaching or a specialist, nor did anyone ever suggest looking into this. We only considered medication to try to curb it.
No one ever mentioned food dyes, synthetic dyes, or how much she is consuming or even that perhaps her medication Atomoxetine was coated in a banned blue dye in every country except the USA. Not even the nutritionist.
We didn't get Developmental Disabilities Administration (DDA) services because my child was not incapacitated and could groom herself, could feed herself, and dress herself. She was high functioning.
When finally, I was going to get the Homebuilders program at my request with CPS, it was too late, my daughter was taken by the family member the day before my Homebuilders program consultation with CPS
I did not receive parent training in de-escalation methods, and the first time I ever heard of the RUBI Autism Network training was in the HCA and WA. Thriving Behavioral Health Groups just last September 2024.
We did not receive adequate nutrition care when she was refusing to eat and drink water, and her safe food were down to about 20, until I placed her myself into a partial hospitalization program
She did not ever get a genetic test that could narrow down the drug interactions of what could work better, what she would have a negative reaction to, and what supplements she would benefit from until I requested one the day she was taken on June 27th 2024, I had to request this after all these years. This did not come from a provider, it came from me.
None of the providers we have went to has a linked behavioral health or mental health database where everyone on her team had access to history, charts, questionnaires, data taken, blood panels taken, evaluations, intakes, medication history, therapies and treatments attempted, providers seen, and feedback over what was working and what wasn't.
None of the providers, behaviorist, behavioral experts, and especially all nonprofits we joined and were involved in told me about the Washington State Community Connectors who just celebrated 10 years of advocating work in our state for systematic change.
None of the places we went to and were in our circles told about the Family Youth System Partner Round Table (FYSPRT) for King County
None of the places we went told me about the Health Care Authority Behavioral work groups or P25, or Washington Thriving. Not even in my special education circles and disability justice advocacy work did anyone tell me about these groups. I only heard about them from Rep Lisa Callan, and Peggy Dolane.
None of the providers told me about the various experts in the field of the nervous system, or a podcast to listen to, or a group to join, or training to join, or a summit or webinar to join. I was given books to read with her evaluations which cost money or time with the library.
What we received was multiple years of PCIT, Talk Therapy, Play Therapy, two attempts at ABA, some form of CBT, and DBT, but there is no proof of this and no data on it from three attempts of Wise/Wraparound.
We got safety plans from some providers, we are some basic coping skills from some providers, we got crisis hotline numbers, and 988 from providers, One CPS worker couldn't be bothered to drop off or at my request email the safety plan to me.
All the safety plans were the same, who are my natural supports? Who can I go to for support? What support groups can I attend? Who in my support circle can I call? Who can give me respite care? What hobbies can I do? Where can I take a mental break? Basic coping mechanisms such as drawing, coloring, games, reading,

taking a bath, candles, and self-care type of things. But none were about how to talk to my child and ask her what is happening to her body or her feelings to be so angry or escalated. None were about how to regulate my nervous system so I could lend her mine. None were about how to keep a full tank of gas in my tank so I could stay present and meet her needs. None were about meeting her needs. Her needs were never determined or identified. A Child psychologist was never recommended either.

I was not told about ways to use non-violent communication; I was only suggested this year by a communications friend of mine who has a PhD in communication.

Sounds all logical right? But it wasn't. An overwhelmed parent trying to survive who is constantly in a state of hypervigilance and in a chronic state of anxiety trying to manage her child's anxiety where both are playing behavior whack a mole.

We attempted medication from Ridlin, Concerta, Guanfazine, Fluoxetine, Methylphenidate, Sertraline, and Automoxetine just to name a few off the top of my head. Some of which have serious side effects of suicide.

This life was like living in the Wizard of Oz and not having the Wizard tell me that having a heart of courage was the answer.

What I needed was simple. Parent training. I needed access to up to date, forward future thinking appropriate care for a child with behaviors from her underlying condition of dysregulation related to extreme anxiety, depression, internalizing, and externalizing her anxieties related to the threat response, or trauma response. I needed crisis response training. I needed an easy system. If this happens, then we try this, if that doesn't work then we try this, if that doesn't work then we try this. I needed a cause and effort efficacy system that was easy for me to follow with my own ADHD and neurodivergent linear thinking processes. I needed a specific safety plan for every type of escalation whether it be verbal abuse, destroying the house, eloping, running away, self-harm, self-injury, animal harm, physical abuse, throwing objects, screaming, mocking, and damaging doors, walls, and windows. I needed to know how to become a low demand parent. I needed all of that broken down into what my reactionary method to use would be my go-to method. I needed degrees of escalation, yellow, orange, red, purple etc.... like the burn heat index signs you see around Washington. I needed metaphors to use with my daughter like animals. She was exhibiting behaviors from like Lions, Tigers, Bears, or such as Robyn Gobbels program Big, Baffling Behaviors she uses owls, possums, and watchdog.

There is such a thing as training the trainer. There should be such a thing as training the parent. There is a well-known quote "Give a Man a Fish, and You Feed Him for a Day. Teach a Man To Fish, and You Feed Him for a Lifetime".

Here is another quote "Surround yourself with others who want to see you succeed". If someone wants you to succeed, they will do everything they can to make sure you will.

What I did instead was become very proactive and sought my own training, and sought my own answers, and sought my own need to understand my daughter's behaviors, where they stemmed from, and what caused them. I needed deep understanding, and I needed an explanation. I am still on this journey, and I am still very proactive in trauma stressors and trauma informed care.

What I don't have is my daughter here to implement these new ways of thinking and reframing of words and ideas. She is my world and will not ever give up on her.

If you would like to contact me further on my lived experience and design mental health programs or systems around what I have written about please feel free to contact me at michellemwhitehead@gmail.com.

My name is Michelle Whitehead, my daughter is Mallory.

I hope you remember her because she matters and she wants to come home. Thank you for reading.