Washington Thriving *(formerly the Prenatal-25)* Strategic Planning Advisory Group
Parents/Caregivers Discussion Group Meeting Summary

Wednesday, October 16, 2024
10:00 – 11:30 a.m.

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Parents/Caregivers Discussion Group Meeting Summary

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Attendees

- **20 Parent/Caregiver Discussion Group participants joined**

OPENING, UPDATES

- The meeting began with introductions and an overview of the meeting goals of providing Washington Thriving project updates, the reporting out of feedback, gathering feedback, and discussing what's next
- The group then reviewed the Full Value Agreement
- This was followed by a brief overview of the overall project which includes
    - 4 phases: Phase 1, visioning (what the vision is and what is the ideal continuum of care)
    - Phase 2, assessing the current landscape (does WA have the right services and supports, does capacity for each meet the need)
    - Phase 3, identifying strategic priorities, and
    - Phase 4, moving to action
- All of these phases are informed by 2 interacting areas of work that cut across all phases:
    - A people centered piece and
    - A data/evidence/research-informed piece
- At this point, the project is in the middle of phase 2

VISION DISCUSSION

- The group then discussed the updated proposed vision which incorporates many of the changes that have been offered over the last three months
    - One participant suggested adding 'trauma' and 'trauma-informed'; trauma informed care is something the state has adopted but she isn't seeing that come up in the Washington Thriving materials; adding it one place should be enough
    - Another said the idea of investing in prevention is good, but sometimes the harm is already done, so how can we restore; she expressed a desire to see not just prevention, but effective restorative services included, those that can help make whole people to whom things have already happened
    - A participant emphasized that children's health develops; her child spent 8 months in prison before she was born, so she's starting off with trauma before she was even out of the womb; we need to think about behavioral health not just from the perspective of looking at fully matured adults, but from a developmental viewpoint; when someone comes here as an immigrant or refugee, you have to help someone get better from where they're at
    - The project team affirmed this is a point worth further fitting into the behavioral health definition: that children's behavioral health is developmental, and progresses through stages, each on of which has an effect on the succeeding stage

PROPOSED DEFINITION OF BEHAVIORAL HEALTH

- The project team then focused on the proposed definition of behavioral health
  - The workgroups converged on talking about services in terms of those all children, youth and families will need, services some will need, and those few will need
  - One participant suggested the "Lead to children, youth, and young adults struggling to navigate life, maintain positive relationships, achieve their educational goals, and adapt to change" bullet point be moved further up toward the top of the list to show higher priority
  - The participant further added that challenges with substances is a symptomatic behavior as opposed to an experience that has caused someone to have behavioral health needs
  - She went on to say one thing she saw missing that parents feel acutely is safe behavior in their children and being safe in the community, as opposed to meeting people online and having inappropriate relationships, running away from home, using drugs that aren't age appropriate
  - Just as parents can impact their children in negative ways, children can impact their parents in negative ways; another participant had said one of his kids didn't feel safe with one of his siblings; there's a need to emphasize the desired goal of helping kids be safe in their behavior, for their own sake and the sake of those around them
  - Another participant said, in reference to the "Children and young adults struggling to navigate life, maintain positive relationships, achieve their educational goals and adapt to change" bullet point, that it's worth noting we put educational goals onto them, so it's not just those that matter— they have their own goals; something they may struggle with is "do I have worth, am I worth the help; do I have worth to live"
  - She went on to say that there are numerous coping tools and strategies, sometimes medicine helps, but if you have the idea within you that you're broken and don't deserve certain things, what are you going to do
  - The participant further said that in the bullet point "Can include a broad range of diagnoses and can change or be exacerbated by lack of intervention," "or lack of acknowledgement" should be added to the end; she mentioned attending a race for school children the day before where kids with disabilities were lagging behind and they were the only ones no one was cheering for; these kids had come because they wanted to belong; this definition might acknowledge the effect that can be wrought on one's behavioral health from not receiving any acknowledgement
  - The project team noted these points highlight an important piece not currently included: belonging, self-worth, and how these intersect developmentally as a child is going through the ages in which they are developing their self-concept
  - The project team also highlighted the point made earlier on regarding the ordering of the points and the expression of prioritization, as there are so many points, and we're reflecting on those specific to child, youth and young adult health that may be different from family systems

CONTINUUM OF CARE

- The project team then focused on the continuum of care
  - The workgroups converged on talking about services in terms of those all children, youth and families will need, services some will need, and those few will need
  - Initial feedback was the continuum of care descriptions were too clinical, and people disliked how the graphic made it look like the path to more intensive services led no where

- The project team showed the group a pyramid visual, broken into categories of services for “all”, “some” and “few”, then asked the group about their experience with services in the “all” category
- Below are the responses that were shared when participants were asked about services “all” would need- such as prevention messages, developmental or mental screenings.
    - One discussion group member said the length of time services are offered to people could also be included
        - The group member went on to say that in King County there are regular wraparound services, if you really have problems you can get CORE, Children’s Outreach; but the duration the services are offered is too short
        - Her daughter with attachment issues was starting to make attachments but got cut off after 12 weeks; that sent her into a worse spiral of behavior; the group member spent a lot of time talking with providers about this but they wouldn’t hear her
        - It’s not just their capacity, but how they’re measuring success, and what does the family really need for long-term stability, because that’s very hard to establish when you have an unstable family, e.g. when you’re going through a divorce; people might need support for years if they have really tough kids
    - Another participant raised the issue a Syrian refugee family experienced when they had a child at age 3.5 who needed services but wasn’t able to get them from WISE until age 6 as they don’t accept children before then
        - The family is still struggling; 12 weeks for services works fine if the issue is stress or anxiety, but if the issues are serious, it takes 12 weeks just to establish trust
        - The discussion group member emphasized the length of time serious issues demand by mentioning she is a therapist and has one client she’s been seeing for 2.5 years who still isn’t healed
    - One participant said she first reached out for services for her child when the child was 3 years old; much of what her family needed was parent education and support
        - Most services out there are trying to separate the child from the parent because the parent may be wrong, but there’s not a good understanding of how important attachment is
        - It takes a big toll on parents who don’t get to be there for any of the big milestones of their kids because their kids don’t reach them
        - She wants to help her grown daughter set lifetime goals and she still doesn’t know where to go for that; she and her daughter don’t have trust that people will be able to help them because of past experiences
        - Everything’s so child-centered and doesn’t look at the impact on the parent who’s supporting the kid throughout their life
        - The project team acknowledged a question one participant raised of how success is being measured, and how parents and providers see that, as a really critical piece
    - A participant brought up how there’s no support in the way the system drops off people and transitions people; it causes so much harm: children with drug problems, homelessness, children who run away, families being shattered
        - She continued that she’d gone through 5 psychiatrists, 4 psychologists, 20 therapists and many programs over 23 years for her children; her daughter went

    to a 13-week wilderness program which was great, then went to a boarding school where she didn't have effective support, then to a peer-based program but that wasn't working, until they really adapted the program to fit her needs; the speaker then tried to help her daughter get back to Washington state and be safe living at home, but the system was so "youth voice youth choice" and because her daughter has attachment disorder and doesn't trust adults, she won't choose the things she needs and won't talk to therapists
    - The project team acknowledged involving families, being trauma-informed, and resources around comorbidities and trauma as things themes mentioned in the chat
- One participant brought up that it is problematic how trauma-informed care is an elective and not a core requirement in masters programs, and it's only 6 credits, which isn't enough; other trainings are 25+ hours; because trauma-informed care isn't taught more widely, in the majority of cases we don't have professionals sufficiently trained to work well with kids who have DID and trauma
- Another participant said children are being regularly retraumatized in schools with shooter trainings or stranger-on-campus trainings; it doesn't seem to reduce trainings and may encourage people to vociferate/think about this; people who've experienced them have to experience their trauma again
- One said that our repeatedly saying "children are resilient" minimizes trauma in children
    - Outside of the official meeting, this participant also said there are 3 hospitals that get a lot of kids, and suggested we get a number to see how many are showing up in emergency rooms; she was shocked at the children's hospital figure of 50,000; she also spoke of the need to think about family initiated treatment, as a cultural value; in family initiated treatment, the child isn't consenting for the first session; the lack of this may be part of what's behind such large numbers in the ER

COMMENTS IN THE CHAT

- Purple seems like a good place to include trauma informed care
- It's healing.
- Orange as Invest in prevention, well-being and healing
- and coping with toxic shame for not being able to live up to the standards society is setting for you...
- maybe change educational goal to lifetime goals
- Self-Worth
- goals for their adulthood... what do they want their adult life to look like?
- This story really hits home on how LUCKY I was that my track team was so supportive of me always coming in last place. my small accomplishments of running against my own time... and giving me a varsity letter not for the races won, but for my heart and spirit.
- maybe as simple as adding the words, "children's behavioral health develops."
- how much of the service is offered should include not just "slots" but length of time it's available to a family
- Waiting list too
- Can you share the link for CORE program?
- CCORS: https://kingcounty.gov/en/legacy/depts/community-human-services/mental-health-substance-abuse/services/youth/crisisoutreach

- How they are measuring the success is exactly the key question. Their idea of what success is and the parents idea of what success are two different things. Also, I got COORS, and they said they can only help for 4 weeks, this was 2019. They only helped me for 3 of those 4 weeks. They literally ghosted me and never responded to text or email. Literally said nothing. Not even a discharge type of conversation or official discharge of program documentation. They just disappeared. I have to log onto another meeting. Thank you so much!
- Thank you for sharing this.
- I echo the experience just shared for parents
- For children with complex PTSD, therapy is typically long-term. Research suggests that trauma-focused therapies for C-PTSD, like Trauma-Focused Cognitive Behavioral Therapy (TF-CBT) or Eye Movement Desensitization and Reprocessing (EMDR), can take 6 months to several years, depending on the complexity of the trauma and the child's progress.
- And we don't always have family or friends for support
- Children with C-PTSD often experience a range of symptoms, such as emotional dysregulation, dissociation, and difficulty trusting others. Therapy can last from 1 to 3 years or longer depending on the severity of the trauma and the child's developmental progress. Pacing is essential, and it's important that therapy is trauma-informed and autistic-friendly.
- I actually believe this is an excellent description of a vision for a kids' BH system. I'm hearing that a few things need to be added:
- or they "think" they know what's best when looking from the outside, but they have no idea what it's like living it.
- Those include involving families, being timely, and trauma-informed.
- https://bupnet.dk/wp-content/uploads/2022/01/PTSD-and-Autism-Spectrum-Disorder_-Co-Morbidity-Gaps-in-Research-and-Potential-Shared-Mechanisms.pdf
- https://link.springer.com/article/10.1007/s11920-022-01331-6
- someone in chat asked me for my recommendations for continuum of care... off the top of my head: early long term in home services with trained peers professionals such as CCORS, but also offer respite and wilderness based short term opportunities to learn peer based emotional regulation skills. in state residential treatment beds for children who are not able to stay safe online or in community.... understanding that introverts don't respond well in group settings such as WISe. schools that have smaller classroom sizes for children with complex needs instead of shoving them all into large gen ed classrooms
- eliminate DCRs and ITA for children aged 0-18 ... unless parents are unwilling to consent to treatment
- redefining what safe and gravely disabled means for youth.
- Can you describe more about this training?
- clear diagnostic criteria for levels of care. ex Self harm isn't harmless "attention seeking"
- must complete trauma informed care, collaborative problem solving, alternatives to natural and logical consequences, attachment therapy...
- That's a hugely important point about the drills the kids go through. Very hard on highly sensitive children and those who have experienced trauma. Really, on all children.
- It's insane. Who is in control of it?
- we used to have tornado drills, I had ptsd from living through one, so I can relate, I think we don't understand how they impact children.