

PN25 Behavioral Health Strategic Plan Parents and Caregivers Workgroup Meeting Notes

Wednesday, May 22, 2024
10 a.m.-12 p.m. Pacific Time

TABLE OF CONTENTS

Attendees.....	2
Breakout Group Exercise: Behavioral Health System Discussion.....	3
Review Full Value Agreement	3
Community Engagement	3
Moving Forward.....	4
Comments in the Chat.....	5

PN25 Behavioral Health Strategic Plan Advisory Group Meeting Notes

May 22, 2024

Attendees

- Rachel Burke, HCA
- Nicole Latson
- Peggy Dolane
- Janice Schutz
- Alexie Orr
- Jenn Anderson
- Jessica Reyes
- Michelle Karnath
- Fay Bosman
- Brandi Kingston
- Karen Kelly
- Rosemarie
- Melia, Kitsap County Parent Coalition
- M. Bordeaux
- Quentesa Garraway, HCA
- Patty King
- Danna Summers
- Jacque Ward

BREAKOUT GROUP EXERCISE: BEHAVIORAL HEALTH SYSTEM DISCUSSION

- Current Behavioral Health system is
 - Adult focused
 - Focused on most intense needs
 - Not much real attention is given to avoiding/preventing situations early on
- The timeline was reviewed: the strategic planning process was proposed in 2022; work began 2023; the deadline was extended, broader membership discussion groups were held, and robust community engagement took place 2024; the strategic plan is due 2025
- More attention should be paid to comorbidities; our list doesn't mention care for people with autism and mental health issues, a combination that is not uncommon
- If arrested, people can supposedly get service in juvenile, but those who get service are those who are compliant and don't have parents pushing back against negative aspects of treatment their kids receive
- Very important to talk about children's behavioral health as being different from adults'
- Shocking to hear we don't think prevention is part of the work
- A diagnosis of autism is an early intervention
- We have to add dyslexia to things we screen for
- When we're not acknowledging differences in learning styles in their makeup, we're going to miss those kids
- Not providing special ed until kids are way down the line causes problems by not acknowledging their conditions sufficiently early on
- Schizophrenia develops over time, not all there at once; fetal alcohol spectrum disorder affects 1 out of 5 kids; it's not just Substance Use Disorder or Mental Health
- Child welfare is part of the problem; we're relying on foster care and courts to manage these problems, which is a punitive/reaction-based system
- Doctors delay giving students in kindergarten a proper assessment when they manifest behavioral issues in class, saying 'we can wait a year, you'll grow out of this' but parents/grandparents want an early intervention, to address this now.
- When teachers notice behavior in kids at an early age and speak up this is good. Not wanting to label your kid can delay their connection to resources they need to cope

REVIEW FULL VALUE AGREEMENT

- Key part of this behavioral health workgroup is to engage deeply with parents, community members and partners. HMA/HCA team is the synthesizers, ensuring what's proposed is reflective of what the group says
- A representative from HCA said that when the Strategic Plan Advisory Group began, they took learning from FYSPRTs and have had a full value agreement at the advisory group level
- The full value agreement has been around for a while but changed recently to its current form; regional FYSPRTs can adopt this and take bits and pieces as makes sense
- A provision was included for what to do if someone freaks out in a meeting
- We have to find a way to deal with people if we don't like what they have to say; one group member expressed the hope that if someone is offended by what she says, they'll talk to her
- One group member expressed a desire to see times included on the agenda, helpful for those with autism who can use help with time management
- Another mentioned a meeting where they had a time-keeper that helped people stay on task and acknowledged how much time had gone by
- Someone wanted to add to the list that we encourage grace, compassion and kindness for 'self' as well as others
- A bullet point could be crafted to remind group members to reign it in or step down if they speak for too long
- We want to remember we're not just drawing from participants' experiences as parents, but from their own experiences
- We decided to revisit the full value agreement at every meeting

COMMUNITY ENGAGEMENT

- Megan shifted gears to orient the group on where we're at on broader community engagement, and materials HCA and others have been developing - do they work, and how close are we to getting info about this right?
- Putting out a mass market engagement strategy:
 - Things we distribute as far and wide as we can, like surveys to reach each group of interest
 - These are places where if people participate in conversations/surveys, these discussions are opportunities for ongoing involvement
 - Hope to incorporate more perspectives as our work proceeds
- More targeted engagement:
 - We recognize there are some people we're not hearing from: those who have historically not had the opportunity to be involved in the process, and those who've had a need for services but have never accessed them
- We'll have some really intensive engagement over the summer:
 - In-person listening events
 - Great partners we're already having conversations with
- In the next workgroup meeting in June we'll preview the further in-person listening events, at which point we can identify what we're missing
- We anticipate this discussion group will be providing updates along the way
- The workgroup will be given the surveys to give feedback on them before they're sent out to the public
- We sometimes get so many surveys we don't know what to do with them; we need warm hand-offs at our various other groups like FYSPRTs
- We need to explain the reasons why a given survey will be meaningful
- The HCA.gov email blast surveys are not a functional way to reach people
- Figure out how to engage people on social media

- One big issue is that our providers have been the stakeholders and we assume they listen, but people haven't had a way of getting their voices heard at the table, so we need to figure out how to make that happen
- We need new distribution channels like this meeting
- One avenue isn't going to be the feedback mechanism that gives us everything, so we need multiple avenues
- The need for being cognizant of the entire state: we don't always hear from other regions, lots of decisions/resources are in one regional hub
- Tap rural communities - people think you can get resources in larger cities across state borders but if you have Medicaid you won't get served there
- HCA acknowledges the non-accessible/non-friendly nature of some of their website content; they're working within a limited budget, but are looking to do some print materials
- They're exploring option of mass marketing work, particularly with some money they have this year that runs out June 30th, which might ask 1 question as opposed to a whole survey, which can be sent out to everyone and serve as an entry place for people who've never had anything to do with this work; the content on the HCA site is still important, but isn't an entry point
- HCA's biggest question is how to reach people who don't even know this work is happening
- Rachel from HCA solicited feedback on her "a vision for the future slide"; a discussion arose weighing the terms 'mental health' and 'behavioral health', and the latter was criticized as being unknown to those who don't regularly show up to meetings, and potentially problematic when providers respond to the term by saying of a situation 'a behavioral issue, willful behavior, not a symptom of diagnosis'
- Printed flyers could be helpful to share with local physical organizations
- One group member thought there's real value in having a person who can actively hand out flyers and converse about them, such as at county, state and school fairs, because having someone who can convey passion about the content of the flyer generates interest in it
- Someone else mentioned that FYSPTs have gone to county fairs, and though they exist they haven't been adequately heard
- Another mentioned that her FYSPT has attended family events, pride fairs, and are trying to get into county fairs
- Someone said we shouldn't rule out places to put flyers even if there isn't a person to hand them out, as when she goes to the local store she looks at the billboard
- The point was made that you should tell people how long the survey you're administering will take
- Surveys shouldn't be more than 2 minutes unless you're paying people
- Is the survey going to have a comments field?
- We get lots of surveys but what's the outcome?
- Someone suggested that it's good to have live polls in meetings like this one instead of surveys

MOVING FORWARD

- There's an opportunity for stipends; in most cases if you're a parent or a young person with lived experience you can receive them
- If you're paid by your employer to be present at a meeting, you're not eligible for payment through this fund; it's in place because most agency/hospital folks are being paid by their jobs to be there, but parents and young people participating as citizens trying to improve things are not compensated as volunteers
- We also have a childcare and elder care reimbursement stipend beyond the \$45/hour one. If there's more than 15 minutes' worth of material to review prior to the meeting, we'll pay you for significant review time, or other activities that relate to this work- we're still figuring out the specifics, but can definitely pay for reviewing
- For meetings like this that are 1.5 hours, we round up to 2 hours of payable time

- Someone mentioned it was hard to get reimbursed last year, and hopefully it will be easier this year for the new people
- Liz Arjun from HMA mentioned a survey going out on how we want to work together around time and date
- We anticipate these discussion groups will meet monthly
- There's no point in doing all of this if it won't work for families, parents, caregivers and youth

COMMENTS IN THE CHAT

P25 Discussion Group with Parents/Caregivers

- The system should be needs based not diagnosis based.
- Labels change depending on age.
- It should also be based on child development and proactive and reactive
- Behavioral health in children develops -- it is beyond mental illness & SUD (SUD is a result of lack of early intervention and prevention). Need a clear definition
- Problematic child welfare system
- FASD, Autism and other developmental issues are not recognized nor funded
- Additional thoughts: parents and family need to be centered in care -- right now our system of care values are individually focused
- Another note: getting an appropriate diagnosis IS early intervention and prevention
- While I agree with the importance of diagnosis, to another workgroup member's point, our diagnosis process is a way of "othering" people...and is the source of stigma
- We've decided that we will do this as a full group
- Already appreciate people sharing candidly
- Culturally competent care and cultural awareness I think is important for children when it comes to addressing mental health challenges instead of using a blanket solution per diagnosis
- I love the statement about grace and kindness to yourself and others
- Younger People?! Ageism view. (this is said gently as a person with a 90 year old mother can do tech)
- There are different communication and learning styles among parents and many of us may be undiagnosed or struggling with our own issue
- Also to clarify- we anticipate these discussion groups meeting monthly along the way
- Recognizing that private insurance families don't connect with state systems until they access public care (often via school IEP)
- And there are regions that are resistant to engaging parents
- Most people access websites on their phones, tiny screens
- Can public health be involved in getting the word out?
- I think anywhere that families would be (libraries, schools, community centers, faith spaces, etc) would be a great place. Even grocery store bulletin boards. I would use the QR code
- If you do a website "billboard" I'd suggest having a link to a "suggestion box" ... for example Rep Berry told me this week she had a constituent who was not able to access their child's mental health record... so there might be a way to solve problems NOW instead of just adding it to the plan
- Mention schools somewhere as they are an important piece of identifying and treating children. It would remind parents of another avenue
- I would provide a definition of BH in children... because "children's behavioral health develops" 10 years ago we used 12 different terms for this at a Navos meeting. We need to use BH because of the adult system, but the education of people is part of the work we need to do
- I don't love the term, however, changing it seems like a daunting task! I like strength-based terms. "Wellness" is a nice term. I also agree with another workgroup member that people don't always understand what BH means. This would be a much longer conversation and brainstorm session!
- Printed flyers would be helpful, as well as digital, so it can be shared in local physical locations.

- In addition to QR code, please include short URL
- Wellness doesn't include FASD interventions
- My question is about accessibility of surveys for different language groups and people with co-occurring conditions
- I would like to see people who are with the address confidentiality program be reached. I am with the ACP and this is a very under-reached population. This is very disheartening considering the people who are in this program have had some kind of DV or SA affect them and their family directly
- Are developmental disabilities included in mental health? People caring for children with autism or IDD might not necessarily think it applies to them
- Also helpful to have other language versions available via the digital link/QR code
- IDD and ASD are the developmental portion of behavioral health in my mind. It's part of redefining how we view these issues... as someone else here said, behavior is developmental and connected to the brain
- Refugees and underrepresented BIPOC Youth?
- Where can people find the results from the survey?
- It would be nice to mention where people can find the results
- HCA's intention is to translate materials for distribution
- Also, we can share many materials on the HCA website
- There's a balancing act between including everything that is likely relevant and what is going to be bite-sized enough that they won't be flooded.
- This survey could be placed as an ad on TV and community boards where people can click on the QR code for further information
- I love the idea of have an additional question on the survey where people can add other thoughts not previously covered
- We need to reach gatekeepers who can reach community members
- I feel that surveys in general are nice to have LIVE while these meetings are in session. I also really like polls. I just agree that many times I "meant" to come back and do them, then never do
- Someone asked if HCA is still helping with childcare during the meetings