The Parent Perspective

Parent Initiated Treatment Advisory Breakout Workgroup: PIT/Age of Consent
Washington State Health Care Authority:
Division of Behavioral Health and Recovery
Friday, August 10, 2018, 9:00-10:00

This presentation is “offered for those interested in talking more about changing age of consent to age 18.”
Overview

• My background
• The problem statement
  • Common goals
  • Assumptions
  • Parent Initiated Treatment issues
  • Unintended consequences
  • Stigma
• A solution is possible
  • Equity & public health perspective
  • Expanding behavioral health umbrella
• Parents Want
• Solving the “Abortion problem”
• Build a solution
Not hypothetical
My Tribe
We raise the age of consent to 18

Either/Or

We keep the age of consent at 13 & fix the loopholes
Shared Goals

• Children get the care and support they need to grow into healthy adulthood.
• The door to accessing treatment is open as wide as possible.
• Keep families intact wherever possible
• We do not have to revisit this issue again!
Our recovery partners tell us...

• “Parent” includes any responsible caregiver/guardian
• Families are the most effective way to raise children
• Family involvement in treatment is a proven best practice.
• Treatment isn’t the same for each youth or each family.
• Treatment for behavioral health struggles isn’t easy – we shouldn’t pretend that it is.
• Most parents want to help their struggling children.
• Transformative growth, restoration and recovery are possible.
What we hear the system telling us

• Workforce shortage
• Not enough funding
• Long wait lists
• The courts are the best way to serve oppositional youth
• Silos are unbreakable
• We’ll invest in prevention, SEL, trauma-informed care & school-based services…
• But not adequately fund special education, school counselors & family support workers
• Lots of parents are unwilling or unable to help
• Youth rights are paramount
• We need to protect youth from parents and defend existing age of consent
• Youth won’t confide without confidentiality assurances
• Abortion is the unmovable political barrier
We want to talk about the big picture!

**Access to Care**
- redefine youth consent
- Entry points: Pediatrician, ER, outpatient community behavioral health centers, schools
- Courts as last resort

**WISE**
- Tiered interventions
- Skills training
- in-home services
- Residential aftercare

**School Based Services**
- SEL/MH Curriculum
- Special Education Behavioral Health Services
- Behavioral health recovery transition schools

**Mobile Crisis Stabilization**
- 24/7, Utah model
- trauma informed care intake
- acute stabilization
- Provider/Parent Education & Training
- Residential Care/Wilderness

**Care Coordination**
- Resource & Referral (PALS)
- medication management
- waitlist reduction
- Break down silos behavioral health/public education silos
- Transparent standards for tiered care
But you gotta know:

Our experience shows us the single biggest barrier to our children receiving behavioral health care is the age of consent.
And our children our dying
Thank you for giving us the opportunity to share our thoughts
False assumptions

- All children have the capacity to understand consent.
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Informed consent:

• Consent must be given voluntarily.
• The client must be competent (legally as well as cognitively/emotionally) to give consent.
• We must actively ensure the client’s understanding of what she or he is agreeing to.
• The information shared and all that is agreed to must be documented.
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• Involuntary residential treatment doesn’t work.
Youth Voice: Olivia

When I was 14 I became very depressed. I had been sexually assaulted at school. I started self harming, my mood got progressively worse, I started using drugs. When I was 15 I became suicidal, I stopped coming home, I stopped caring completely.

My parents were able to get me to a counselor who was able to diagnose me with drug abuse, depression and anxiety. He told them that they had to act quickly and find me a treatment center. In Washington I was medically emancipated so I could sign myself out if I wanted to. I would have!

My Mom took me to treatment out of state against my will, I was angry at my parents for a long time.

When I was suicidal I didn't want help. I wanted to die and I didn't want anything to stop me.

I was in residential treatment for 18 months and graduated treatment at 17. I'm 22 now. I'm happy to be alive and so grateful they found me help.

If my parents hadn't taken me out of state I would not be here.

I'm asking that this law be changed so that other parents can get their children help they need here at home.

I believe we need to raise the age of consent for mental health to 16 or 18.
Open our minds to new ideas
Parent Initiated Treatment Issues To Fix Today

1. Parents are not able to collaborate – nor confidentially share information – in their child’s care, thus a therapist is unable to fully understand the child
2. Requires involvement with the courts and bureaucratic hoops to get long term treatment
3. Relies on jail and foster-care for interventions on most-at-risk, hardest to serve
4. Prevents parents from being able to bill insurance when a child refuses to share records.
5. System-focused illness-based model instead of trauma-informed, family-centered wellness
6. Consent forms trigger trauma-responses in youth and can even lead to suicide or runaway attempts
7. Limits access to early interventions and access to safety net services (WISe) and enables defiance by youth
Today’s Parent Initiated Treatment Issues

8. Stigmatizes parents. System that assumes parents are the problem and do not understand their child’s needs. (Sometimes nobody understands!)

9. Excludes the most knowledgeable person (the child’s care manager) who also has the most to lose

10. Only provides short-term stabilization

11. Untested in SUD and as of 4/1/18 parents no longer can consent to inpatient substance abuse treatment

12. Assumes all children are capable of informed – and discounts the importance of trauma-informed interventions & adolescent brain development

13. Parents are not able to collaborate – nor get information – in their child’s care, thus a therapist is effectively able to fully understand the child
Unintended consequences
Addicted, homeless and incarcerated

Out of state care: 34%
Moved out of state: 33%
Incarcerated: 11%
Homeless/opioid addict: 22%

MY SON'S FRIENDS
School to Prison Pipeline: POC

General Population
- Black
- Other

Juvie Population
- Black
- Other
School to Prison Pipeline: Disabilities

General Population

Juvie Population

- Disabled
- Other
Have you heard about the Hospital to Prison Pipeline?
“With 24 hours of checking himself out of the hospital, my 13 year old was in jail – where he finally received a referral to CLIP.”
Our system spends money making our children worse

- Unhealthy children treated as juvenile offenders and expected to behave like adults.
- Many threats to children’s health are not considered under the definition of medical necessity but lead to long-term system costs.
- System requires multiple failures – including police involvement and jail -- to get assistance without protecting child during this time.
- Parents are viewed as the problem and shamed when seeking help.
- Yet wait times are long and services scarce...
Troubled teen treatment brings hundreds of millions to Utah economy — August 7, 2016

6,400 jobs
$269 million in earnings
$423 million in state gross domestic product
$22 million in state and local tax revenue

• “It takes work, not only from the "troubled teen" who is facing any number of neurological, social, emotional, mental or behavioral issues, but the entire family system must be committed to making it work.

• "Most kids fight it at the beginning ... but they get used to it. For some kids, it's a hard process. Ideally, their parents are on board.

• Families end up being an integral part of programs, with sibling and parent visits factored into the plan, to help everyone learn skills and see the participating child adapting and growing from their new environment.
System by-product: stigma

I have had to deal with juvie because of my son. It hasn’t been a very good thing for him, but for a parent it’s even worse. They look at parents like you’re the enemy. I’ve been ignored, not even acknowledged when I’m right there next to my son, and they take him in another room and exclude me. The staff have no compassion for a caring parent, and they are not very happy to answer or assist me when I have questions. This includes, ARY staff, probation counselors, etc.
Stigma: Blaming the parents

I am tired of being accused of bad parenting to cover up the lack of mental health care awareness or accessibility,...and the assumption by the public and people in the system that I am simply not utilizing that, which is in their mind, readily available.
Stigma: hurdles to access care

“We’ve experience ongoing rages, threats of suicide, destruction of property, weapons, school failure, paranoia, homicidal ideation.....and yes, lots of police contact, juvenile justice contact, ER visits, counseling, therapy....and we still hadn't met the criteria for filling out the paperwork to ask to be on the waiting list for residential.”
Denial Stigma: It often takes parents longer to seek help.

Ms E. [from my daughter’s] middle school told me that she thought we needed serious help. I just did not hear it at the time.
Optimism Stigma: Parent’s are often told they are over anxious.

From 2nd grade on I knew there was something different about my daughter, but everyone kept telling me to relax, she’d grow out of it. By the time we got help, it was too late.
When least restrictive options fail, then what?

“’I’m at my wits end with school refusal! He made it to 4 days of summer school. That’s it. He’s even stumping the behaviorist from CCORS.”
Even suicidal children aren’t receiving care

Can’t tell you how many times I’ve called when the cops come and my child isn’t dead (because I caught him in time while he had a belt around his neck in the act) or bleeding [and] had to push the police to take him to the ER. One time I was told [by the 911 operator] to drive him there myself -- this is while I am hiding to protect myself after he assaulted me and tried to kill himself.
System failure impacts the whole family

I was dangerously close to losing my youngest 2 because of my oldest son's violence, but had no recourse. They told me my only option was to sign him over to them, at which point they refused to take him. My husband and I have actually discussed divorce so that he can keep the younger ones, when I'm charged with endangerment for having my oldest in the home, or charged with abandonment for refusing to bring him home from the ER so that I don't endanger the younger ones.
Foster to adopt parents view age 13 as a dangerous threshold

We keep hoping to reach a point where no one is in constant crisis, but with five kids with special needs this hasn't happened in about six years.

The irony is that we can speak firsthand to the inequity of services offered between different categories of disability.
Parent Voice: Ellen
A message from parents:

We do not trust the system to make behavioral health care decisions for our children, because it has failed them miserably.

It was 1978 when the age of consent law was lowered. 40 years of loophole fixing!
We can do better!
Address needs beyond acute stabilization

- Cognitive processing disorders
- Expressive/receptive language disorders
- Family relational issues
- Attachment issues
  - Under age substance use/abuse
  - School refusal
- High ACEs
- Autism
- Extreme emotional dysregulation
  - Weapon ownership without parent consent
- Reactive Attachment Disorder
- Oppositional Defiant Disorder
- Conduct disorder
- Borderline Personality Disorder
- ADHD
- Precocious sexuality, sexting, gender dysphoria
- Self Harm
- Bullying others
- CSEC, gang membership & illegal behavior
Expand our vision of **Behavioral Health**
View problem from a public health lens

• Are we furthering our understanding of root causes, are we interrupting harm, and are we helping to place this youth on a pathway to wellness?
• Are those most affected centered in our discussion about this issue?
• Is this action duly informed by an understanding of this child’s development?
• Will this action help eliminate racial and other biases in practices or outcomes?
• Does this decision and the nature of its implementation promote a path to success?
• Are we fully recognizing youth’s [and family’s] capacity for growth in making this decision, policy, or program?

via Best Starts for Kids
Hold Equity as our Core Value

• Equity is an ardent journey toward well-being as defined by the affected.

• Equity demands sacrifice and redistribution of power and resources in order to break systems of oppression, heal continuing wounds, and realize justice.

• Equity is disruptive and uncomfortable and not voluntary.
Parents Want: Family Centered Approach

1. Ability to make medically necessary behavioral health care decisions for our minor children
2. Ability to communicate with providers who are caring for our children, including medication management
3. Mandated involvement of parents/caregivers in child’s treatment unless documented otherwise
4. Access to residential care without needing an ITA, multiple levels of state approvals, or court intervention
5. Stop using jail and foster care to “treat” deviant behaviors. ARY/CHINS must be part of the solution.
Parents Want: Family Centered Approach

6. Provide in home services for resistant children including Dialectical Behavior Therapy (distress tolerance & emotional regulation skills training), respite care, and Functional Family Therapy

7. Clear standards of admission practices for tiered levels of care/intervention

8. School-based services that include behavioral health supports for IEP & 504 students

9. Not being shamed for needing more help than the average family.

10. Minor children are able to access care without our consent, but parents are involved as early as is prudent
Parent Want: protect children’s rights

• **Do:** Allow minors 13 years or older the ability to seek out behavioral health treatment without immediate parent consent
• **Do not:** require providers to treat a minor nor make disclosures to the child’s parents if, in the judgment of the provider, doing so would put the child at risk of harm.
• **Do not:** provide parents access to psychotherapy notes.
• **Do not** hold healthcare providers liable for communicating with a parent about their child’s evaluation or treatment.
Reproductive health is not on the table

Parents are not here to change the right of any child to receive an abortion nor impact laws that allow children 14 and older to receive testing, reproductive healthcare, contraception and treatment for STDs without their parents’ knowledge. This is a non starter and a red herring.
6 NARAL Blue States

- California (CA)
- Oregon (OR)
- Washington (WA)
- Montana (MT)
- Connecticut (CT)
6 NARAL Blue States

- California (CA): 12
- Oregon (OR): 14
- Washington (WA): 13
- Montana (MT): 16
- Connecticut (CT): Any age

[Map showing states]
All NARAL Blue States have more parent rights to access care than Washington.

- California (CA) - 12
  - Parents may consent to care up to 18, must be involved in treatment plan

- Oregon (OR) - 14
  - Parents may consent to care up to 18, must be involved in treatment

- Washington (WA) - 13
  - Parents may initiate treatment only

- Montana (MT) - 16
  - Parents may consent to care up to 18

- Connecticut (CT) - Any age
  - Up to 6 sessions without parent consent

- Parent consent to 18, parent must be included, (PA)
New ideas to open access to care

• Fix the Loopholes
• Child Initiated Treatment
• Raise the Age of Refusal
Fix the loopholes

When a parent brings a child in for an evaluation and the provider determines that treatment is medically necessary, then the parent becomes the personal representative for the child during the course of treatment.

- Include protection for provider so they are not be liable for communications with the parent of the minor related to the exchange of information or treatment discussions.
- The provider is not required to enter into a treatment relationship or make disclosures which would, in the judgment of the provider, place the child at risk of harm.
- The obligation to share treatment information with a parent shall not include a right of access to psychotherapy notes.
- Do not authorize disclosure to the parent of information relating to the substance use disorder treatment of a child to the extent that this disclosure is prohibited under federal law.
- The parent shall be considered the personal representative of the minor for the purpose of transmission of medical information, making treatment decisions, and reviewing the compliance of the minor with treatment recommendations.
Flip the equation: Child Initiated Treatment

• Parents can access healthcare for their minor children up to the age of 18 regardless of whether it is physical, behavioral, or mental (with the exception of reproductive health)

• Abolish Parent Initiated Treatment because of the stigma it create.

• Create a Child Initiated Treatment Process that allows a child of any age to access care that protects youth over 13 who want to access services without parent consent and protects their medical records.
Raise the age of refusal: Family Centered Care

Let’s learn from other progressive states starting with 2016 Hawaii Revised Statutes concerning children’s outpatient MH.
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