Washington State Health Care Authority

REPORT TO THE LEGISLATURE

Family Initiated Treatment (FIT) expansion

Survey results impact report

Engrossed Second Substitute House Bill 1874; Section 24; Chapter 381; Laws of 2019

November 1, 2020

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Survey results impact report

Washington State Health Care Authority

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Executive summary

Parent Initiated Treatment (PIT) was expanded to Family Initiated Treatment (FIT) through Engrossed Second Substitute House Bill (E2SHB) 1874 (2019), the Adolescent Behavioral Health Care Access Act, and Substitute House Bill 2883 (2020). FIT is an admission pathway for youth age 13-17 in Washington State that currently includes access to mental health and substance use services across the continuum of care. FIT requires that youth meet the medical necessity to receive outpatient evaluation and treatment services, and inpatient evaluation, hospitalization, and residential treatment. The current law applies for youth age 13 through 17 and requires that mental health and substance use professionals protect the rights of the youth to seek care independently while also assuring that parents, per the expanded definition in RCW 71.34.020(46), are provided the opportunity to participate in treatment decisions for their children. RCW 71.34.010 reads:

> "…minors in need of behavioral health care and treatment receive an appropriate continuum of culturally relevant care and treatment, including prevention and early intervention, self-directed care, parent-directed care, and involuntary treatment."
>
> "Additionally, all behavioral health care and treatment providers shall assure that minors' parents are given an opportunity to participate in the treatment decisions for their minor children. The behavioral health care and treatment providers shall, to the extent possible, offer services that involve minors' parents or family."
>
> "It is also the purpose of this chapter to assure the ability of parents to exercise reasonable, compassionate care and control of their minor children when there is a medical necessity for treatment and without the requirement of filing a petition under this chapter, including the ability to request and receive medically necessary treatment for their adolescent children without the consent of the adolescent."

As a result of E2SHB 1874 (2019), the Adolescent Behavioral Health Care Access Act, the Washington State Health Care Authority (HCA) was directed to do a yearly survey to "measure the impacts of implementing policies resulting from chapter 381, Laws of 2019 during the first three years of implementation." RCW 71.34.3871 reads:

> "The Authority must report on the results of the surveys annually to the governor and the legislature beginning November 1, 2020. The final report is due November 1, 2022, and must include any recommendations for statutory changes identified as needed based on survey results."

This report is the first of the yearly FIT survey report required by the 2019 law. As such, HCA intends to use the data received as a baseline to observe change over the course of three years. We will use the baseline data to understand how and where the efforts that were made to educate and

introduce FIT to Washington State have had successes, and the additional opportunities to educate and inform the system. In addition, we intend the survey to assess the system to better inform on the barriers that are experienced through the use of FIT as an access point to all levels of behavioral health services.

Background

The 2020 FIT survey, developed by HCA, was created as a baseline to assess the system impacts of FIT. The survey was developed with three main pathways, one specific to parents and community members, one specific to youth or young adults with lived experience, and one specific to providers of all types.

The questions were developed using a diverse team and an effort to consider all lenses, including youth peer, family peer, subject matter experts, and HCA's children, youth, and families, quality and research manager. The team worked to develop, provide feedback, and edits to the survey questions for each system group. Significant time was spent on the survey development to ensure the survey results would deliver baseline data on the system's understanding of the FIT roll out. The survey was kept to a shorter more concise set of questions hoping that the time requirement would allow for a greater amount of respondents.

The survey was sent out by HCA's communications team to a broad audience of behavioral health providers, advisors, stakeholders, state agency partners, the statewide family youth system partner round table (FYSPRT), and shared on social media, and FYSPRT social media accounts to ensure those who were interested had access and knowledge of the survey and the opportunity to provide feedback.

The survey was open for approximately one month, between May and June 2020, and was accompanied by educational materials on FIT as well as the other access points available through RCW 71.34. There were multiple efforts to engage respondent feedback, to ensure the survey had balanced voice and perspectives. Ultimately, responses from youth and parents were low and provided for more creative outreach in future years.

Findings

FIT survey overall respondent breakdown

Most of the 2020 FIT survey respondents selected the provider identifier with 137 respondents identifying as a behavioral health provider, 68 respondents identified as parents, and only 11 respondents were youth or young adults with lived experience in the behavioral health system.

Not all survey respondents answered all questions. The survey contained "skip patterns," so respondents were asked only to provide answers to those questions that were relevant to them.

Additionally, some respondents skipped over questions that were presented. Table 1 shows the total breakdown of all survey respondents.

Table 1: Total respondent breakdown for the 2020 FIT survey

Respondent category	Total
Youth	11
Parents *as defined by RCW 71.34*	68
Behavioral Health provider	137
Total of all respondents	**216**

Youth survey

The youth survey pathway had by far the least respondents of the survey. With only 11 of the respondents identifying as a youth or young adult with lived experience, HCA has identified the need to create more opportunities for youth to access and take the survey to ensure that feedback received is from as many voices of those impacted by FIT as we can across the system.

- Of the youth surveyed, half had heard of FIT before, and half had never heard of FIT.
- 2 of the youth respondents believed they had accessed services through FIT or its predecessor, PIT.
- Youth who responded understood FIT or its predecessor PIT as the act of the parent signing the consent form on their behalf, with all youth respondents saying that they did not sign the consent form when their parents initiated FIT or its predecessor PIT.
- 3 of the youth respondents have sought behavioral health service without the knowledge of their parents through Adolescent Initiated Treatment (AIT).
- In the survey, we asked youth respondents what helped them when they started the search or were initiated into the process of starting behavioral health services. Youth respondents said that they started with a supportive family member; others said their internet research.
- When asked what helped the youth when seeking services, respondents said supportive family members and trusted school counselors helped them. One youth wrote an open- ended response about the need for privacy as an aid in their search for services: "*knowing records were private and protected from anyone except who they released them to, and that their service professional could withhold information if it was determined to be harmful even if a release was signed.*"
- The youth were asked what challenges or barriers they experienced when seeking mental health or substance use treatment services. The two respondents who provided additional information said affordability was a factor in their ability to access services.

Perceptions of FIT among youth

When asked about perceptions regarding FIT, youth responded with concerns about perceptions parents hold about having a right or needing to know everything to do with treatment services that youth are receiving and the potential breach of a youth's rights, dignity, and the potential to be a strong deterrent to engage or participate in care if their information might be freely shared. Additionally, youth were split on their overall perceptions of FIT.

- Respondents were divided equally in their beliefs about FIT point that could help young people get the services they need. Respondents were equally divided between agreeing and disagreeing.
- Youth believe that FIT helps the parents of young people who need services. When asked this, 3 respondents choose between somewhat or strongly agree, and none chose somewhat or strongly disagree.
- 2 respondents believe that FIT may violate the rights of a young person. In contrast, one disagrees strongly that it would violate youth rights.
- No youth respondents had concerns about FIT not being enough of an intervention to help parents get youth access to services they need.

Below is an additional comment from a young adult respondent on youth perceptions of FIT:

> "In a room devoid of youth, I see a pattern of privilege emerging. This pattern is one of the parent/caregiver assuming and/or demanding to know the details of the youth's therapy. It's a disturbing trend and one that must be watched carefully. While there are many loved ones that just want the basics in order to provide love, care, and assistance; it is a slope that can cause additional trauma if all parties do not understand and accept that the heart of therapy is NOT for general dissemination. I was lucky in that my parents, when I was 16, respected my right to privacy AND insisted that I attend. They created a safe place for me to get well. It's important that those in crisis get that same assistance under the FIT legislation."

Parent survey

Sixty eight parents responded to the FIT parent survey. The respondents had representation from 18 counties in Washington State, with about half from King, Pierce, and Snohomish counties. All but one respondent identified as a caregiver of a youth or young adult under the age of 18.

- 38 respondents said youth in their care received services before age 13.
- 15 respondents said youth in their care started services between the ages of 13-17.
- 5 respondents said that youth in their care had accessed services without their consent or knowledge through Adolescent Initiated Treatment.
- 42 respondents do not think their youth had accessed services independently.
- 5 acknowledged that they do not know if youth in their care had accessed services independently.
- 30 respondents were aware of FIT before taking the survey, 22 were not.

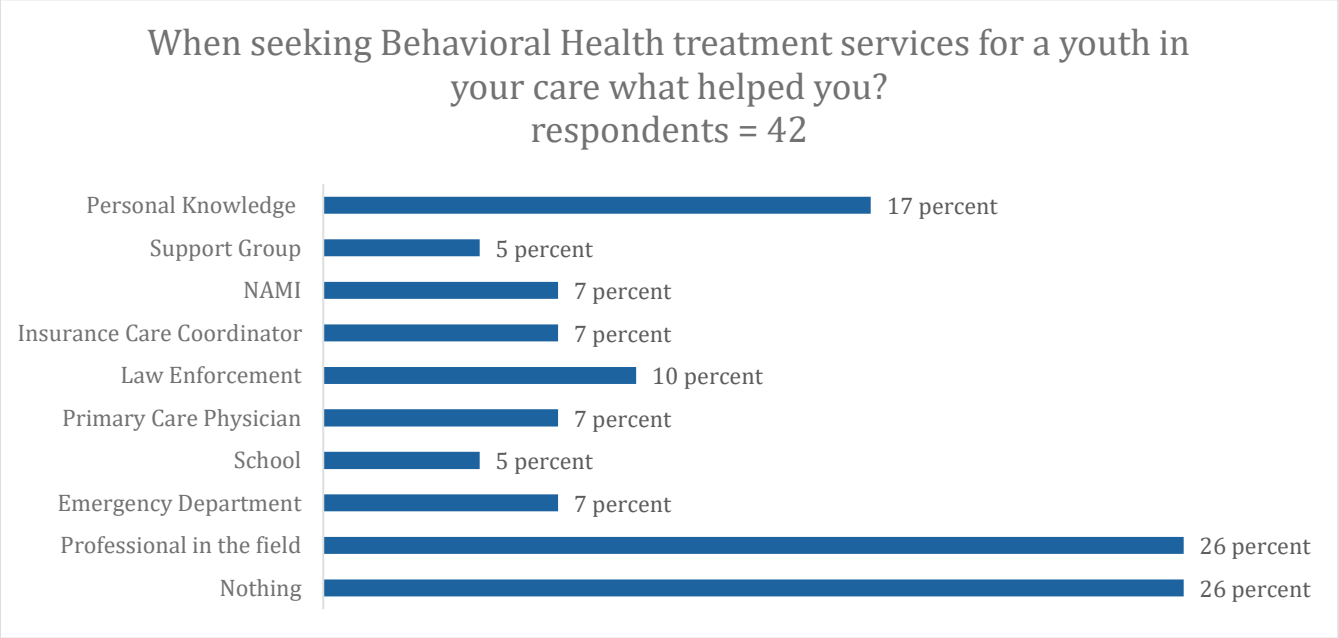
- 18 respondents attest that they have initiated FIT.
    - 7 said the youth still signed consent to treatment.
    - 7 believe they have initiated FIT for a child under 13 years of age.
    - Of the 18 who initiated FIT, 17 respondents provided relationship status to the youth:
        - 10 initiated FIT for their biological child
        - 1 initiated FIT for a stepchild
        - 1 initiated FIT for a foster child
        - 3 kinship caregivers initiated FIT
        - 2 adoptive parents initiated FIT
- 17 parent respondents began seeking access to services through their primary care doctor first. Other access points include:
    - Community program (9 respondents)
    - School (4 respondents)
    - Friend (2 respondents)
    - Crisis line (1 respondent)
    - Other (9 respondents) including: Online search, emergency department, current therapist, law enforcement

Parents were asked, "When seeking behavioral health services for a youth in your care what helped you?" We reviewed the open-ended responses provided by 42 parents and identified multiple categories to capture themes for what helped them when seeking care. The resources for help included:

- Personal knowledge
- Support groups
- National Alliance on Mental Health
- Insurance care coordinators
- Involvement by law enforcement
- Primary care physicians
- School supports
- Emergency departments
- Other professionals in the behavioral health field
- If they felt there wasn't help available to them.

Their responses are reflected in Graph 1 on the next page.

Graph 1: What helped parents when seeking behavioral health services for a youth in their care



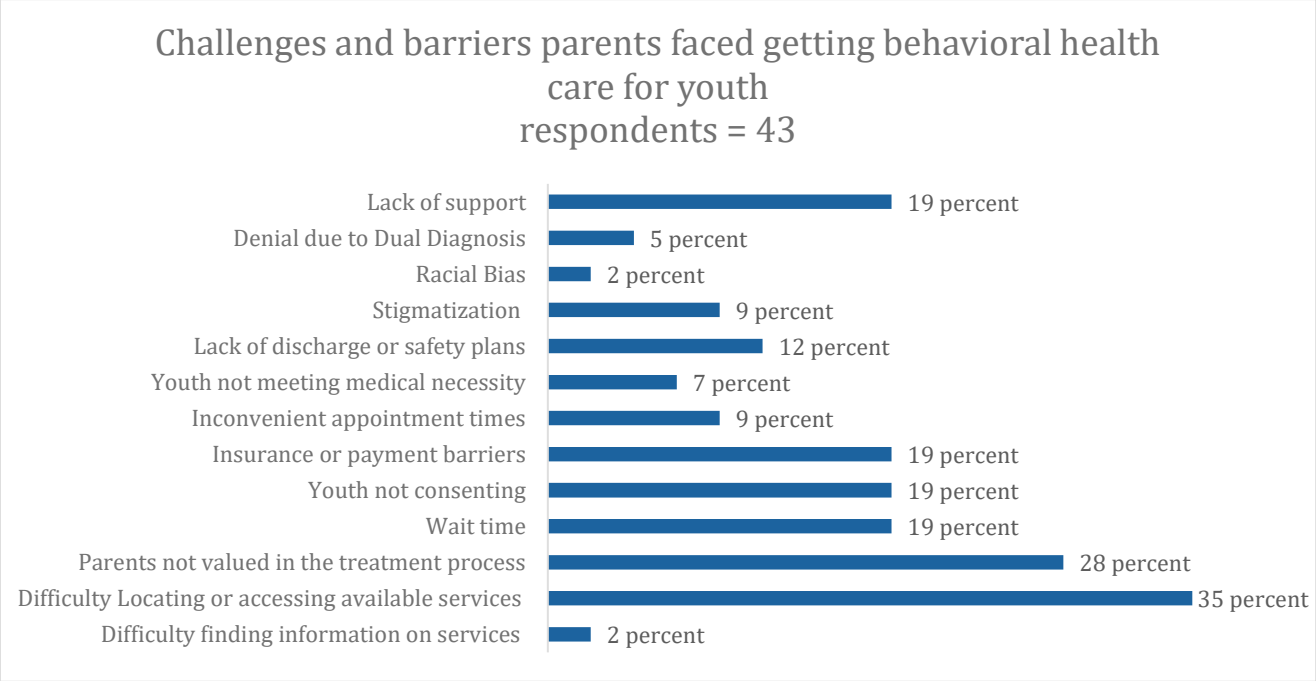
Perceptions of FIT among parents

Parents were asked, "What challenges or barriers did you experience when seeking MH or SUD treatment services for a youth in your care? This includes seeking services through FIT." We reviewed the open-ended responses provided by 43 parents and identified multiple categories to capture the relevant content and themes for what helped them when seeking care. Those themes included:

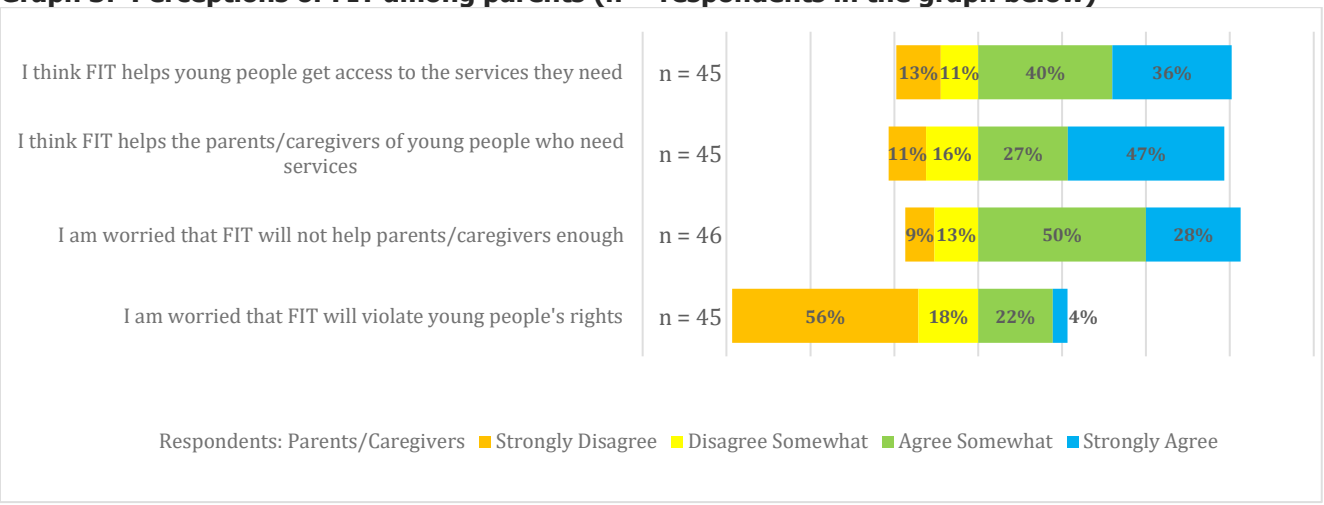
- A general lack of support
- Denial of services due to dual diagnosis of mental health and substance use disorder
- Racial bias's from the provider giving care
- Stigmatization
- Lack of discharge and/or safety plan
- Their youth not meeting medical necessity for the treatment sought
- Inconvenient appointment times
- Insurance or payment barriers
- Their youth not consenting
- Provider wait times
- Not feeling that they as parents were valued in the treatment process
- Difficulty locating or accessing services
- Difficulty finding any information on services.

Their responses are reflected in Graphs 2 and 3 on the next page.

Graph 2: Challenges and barriers parents faced getting behavioral health care for youth



Graph 3: Perceptions of FIT among parents (n = respondents in the graph below)



Below are some of the remarks from parents on their perceptions of FIT:

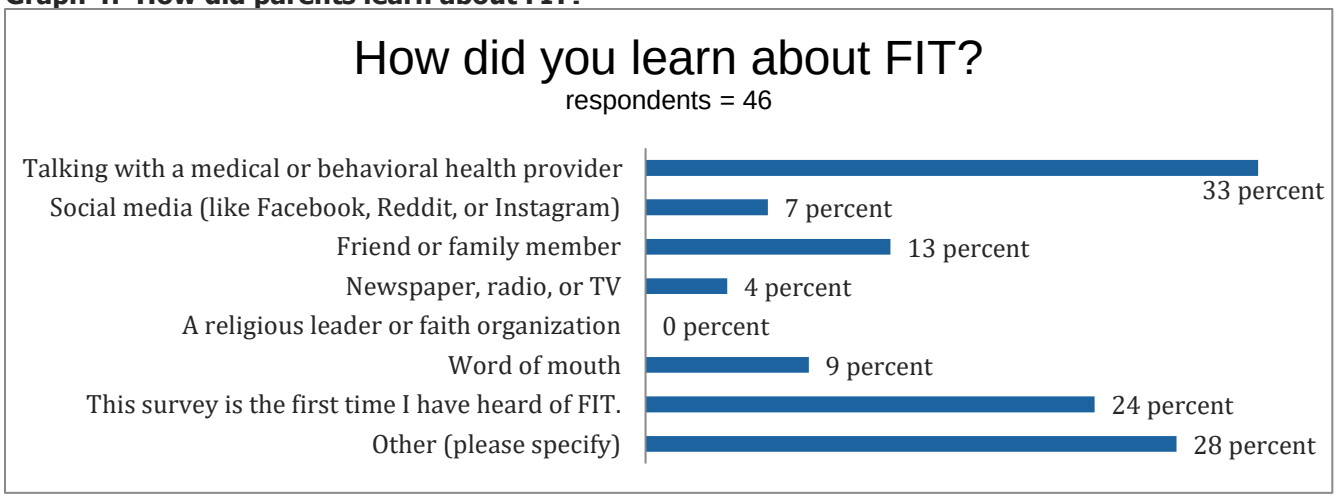
- "There needs to be more support and services for youth in crisis who have co-occurring disorders. They should not be discriminated due to their disability."
- "When I've been able to get access to FIT, I was ostracized from the process, treated like I was an overbearing parent, and my child was given treatment as if he signed in voluntarily."
- "My daughter is now 18 and so doesn't qualify for FIT and our daughter was agreeable. But I know many parents who could have benefited from FIT to get their child counseling."

- "Our state is doing a disservice to youth. They are not capable of making their mental health choices. Instead we allow them to make these poor choices until they are 18 and then they end up in jail or dead."
- "Each situation is so unique. While I support parents being able to obtain services for their child who may not be amenable to such help, I am not sure that forced treatment for adolescents has been shown to be effective. Furthermore. I have known several children who were in abusive environments who were forced into treatment when the real problem was the unfit/abusive parent (s). Each situation has to be thoroughly vetted to ensure both safety of the child and help for desperate parents. Use of youth peer supports is critical!!"
- "FIT was not available when my child needed it most, leading to long term incarceration for violent behavior."
- "I believe scarcity and inaccessibility of mental health services for kids is a much greater problem than parents lacking more power to coerce their kids into therapy."
- "I believe it's important that the child/youth has an advocate who knows the systems, the options, professional language, knows how to truly listen and is seen by the other professionals as an equal part of the team."

How parents learned about FIT

Parents were asked "How did you learn about FIT?" Their responses are shown in Graph 4.

Graph 4: How did parents learn about FIT?



Respondents who selected other said they heard about FIT through:

- HCA's website
- Family youth system partner round table
- Following the legislation
- Through a parent advocate

Additional comments from parents about FIT

Parents were asked if they had "Anything else you would like to share with us about your experiences with mental health or SUD services or FIT?" There were overwhelming responses to this open-ended question. Some of what they had to say includes:

- "Young people have a difficult time asking for help. When I was looking for a counselor for a family member very few were accepting new patients. I made many calls just to find someone. It would have been helpful to have a list of qualified youth counselors who could immediately see a new client."
- "I had to file ARY petition years ago to get my daughter into treatment. It is a good thing to make it easier to get young people in treatment whether they "want" or not."
- "Families being able to initiate care is a good thing. But, the continuum of services desperately needs broadened to include a higher/longer term level of care than CLIP. There are chronically violent youth in the state who have already been through CLIP (some, multiple time) who are all ending up in jail our out of state because we don't have a long term resource to meet their needs. We need to make one, as it is both traumatizing kids and families, but also creating a blossoming public safety risk as chronically violent youth (who have already done CLIP) have nowhere to go to meet their needs."
- "Give parent/caregiver better access to help for youth besides police.
- "…Hopefully FIT will err on the side of care, just as if we were treating cancer or diabetes, or a cast on a broken limb or any other medical condition that a child might not want to participate in because it was boring, took up their time, was uncool, seemed pointless, their friends or they didn't see any reason for it."
- "There were several themes around the pain that families are in and their need for help."

Provider survey

Most of the respondents of the 2020 FIT Survey were providers, with 137 respondents identifying as a behavioral health provider. Providers from more than 20 counties in Washington responded to the survey, with the most significant representation from King (28 percent) and Pierce (14 percent) counties. Tables 2 and 3 (on the next page) display how providers describe their organization. Some respondents chose more than one description. Providers were also asked how many FIT admissions their organization admitted within the past year. That information is in Table 4.

Table 2: Providers (respondents = 120) describe their organization

Which of the following describes your organization?	Responses
Outpatient behavioral health treatment	59
Inpatient behavioral health treatment	17
Provides substance use disorder (SUD) treatment services, but not mental health treatment	9
Provides mental health treatment services, but not substance use disorder (SUD) treatment	15
Provides co-occurring treatment (both mental health and SUD treatment)	32
Foundational Community Supports like supportive housing and/or supportive employment	19
Acute care evaluation and treatment center	6
Other (please specify) see breakdown in table 3	41

Table 3: Breakdown of the "Other" category (respondents = 41) from table 2

Breakdown of Other	responses
Acute care evaluation and treatment center	2
Family Therapy	2
Developmental Disabilities Administration	2
Substance use disorder professional	1
Department of Children, Youth, and Families	3
Administrator	5
Legal Aid / Court	4
Primary Care Physician	2
Crisis Services	5
Wraparound with intensive services (WISe)	3
Emergency Department	2
School-based health services	4
Community Programs	5
Prevention and Intervention program	1

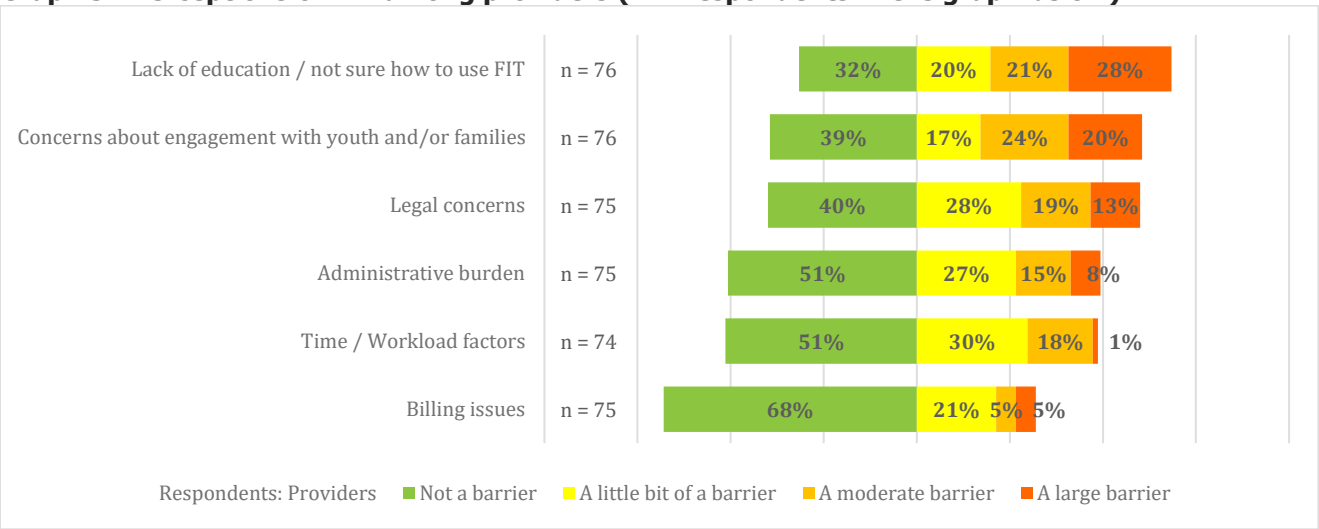
Table 4: Provider (respondents = 105) identified number of FIT admissions by their organization in the past year

How Many FIT admissions, where the parent signs the consent, has your organization had in the past year?	
Answer Choices	Responses
None	63
1-10	28
11-20	2
21-50	3
51-100	3
100+	6
Other (please specify)	16

Perceptions of FIT among providers

Providers were asked about the barriers they faced that impacted their organization's use of FIT. As shown in Graph 5, the most substantial barrier identified by providers was lack of education or understanding of how to use FIT, with about half of providers citing it.

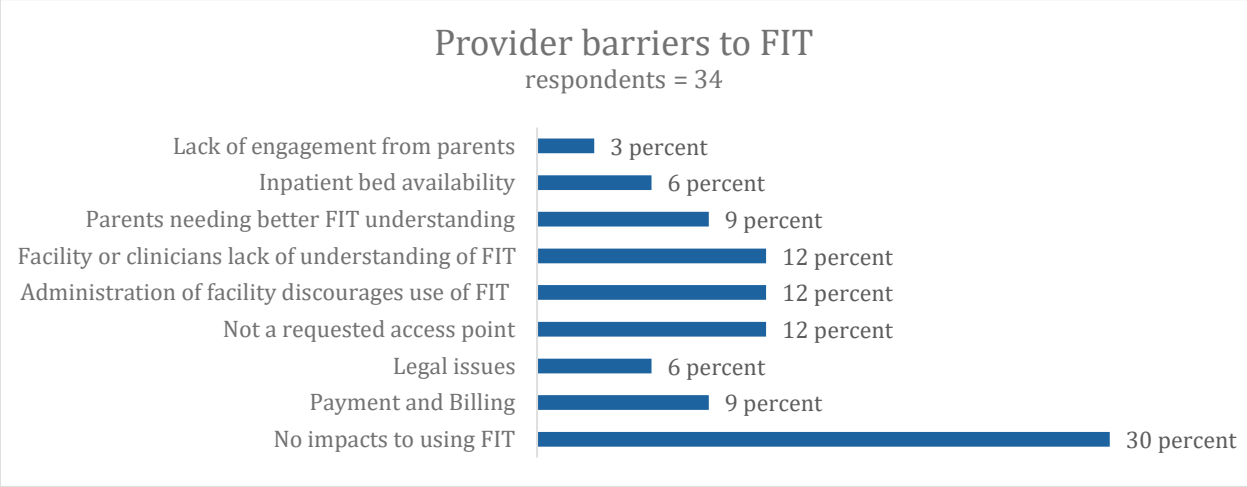
Graph 5: Perceptions of FIT among providers (n = respondents in the graph below)



Other responses providers gave about the barriers they face include:

- "I don't even know what you're talking about. That's an issue. Agencies don't share this information with their staff."
- "We find FIT is generally not needed for intensive in-home outpatient services. We describe WISe as a family-oriented approach and our staff work hard to engage youth to participate. For some youth our staff are in the home multiple times meeting with family members before successfully engaging the youth, but nearly always the youth eventually participates. Generally the youth becomes well engaged, even when initially extremely reluctant. We have an advantage as we provide services in the home at times that work for the family. Our Peers are also particularly effective in engaging reluctant youth."
- "The Parent understanding that the youth still has to meet criteria for psychiatric admission."
- "Parents we have encountered who want FIT have either asked about converting their children (who are already actively engaged in treatment voluntarily) to FIT cases (so that they can have access to their children's information without their children's consent) or have brought their children to our office under false pretenses. When they arrive, parents aren't even able to get their children out of the car to complete an intake assessment, and we will not admit a child into our program without completing an intake that includes the child."
- "Services are simply much more effective when we are able to engage a youth. We see engagement as our primary role - if we are not successful we know our approach needs to change. We don't give up, but we try various different approaches until we find one that feels right to the youth and family."

Graph 6: Barriers to FIT identified by providers



Providers were asked about what additional factors had impacted their organizational use of FIT. We reviewed the open-ended responses provided by 34 providers and identified multiple categories to capture the relevant content and themes surrounding what impacted their use of FIT. Those themes include a lack of engagement from parents, inpatient bed availability, parents needing a better understanding of FIT, Facilities or clinicians needing better understanding of FIT, administration of the organization or facility discourages the use of FIT, FIT has not been requested, legal issues, payment and billing, and that they have had no impacts to using FIT. Their responses are reflected in the Graph 6, above. Here are some additional quotes from providers about the impacts of using FIT.

- "It just hasn't come up often. Getting the consent is generally not the problem - getting true engagement is."
- "Red tape, required paper work, releases and incorrect information or varied paperwork and requirements required by BHO depending on who you talk to. Encrypted email communications that often have glitches and general misunderstanding between person attempting to illicit authorizations and people making decisions on these authorization requests."
- "Lack agency policies on interpretation of FIT."
- "We try not to use FIT unless alternatives don't meet the need of the patient."
- "Parents often think that FIT guarantees admission. The youth still has to meet medical necessity for that level of care, which is hard to explain to parents at times."

Providers were asked if they had suggestions or recommendations on how FIT could be improved. 31 respondents provided information. Below are some of their responses.

- "Streamline the process and make it the same for everyone accessing or attempting to access the system."
- "Training ED and hospital social workers."
- "I don't think families are aware of this option- if they are, I think more would choose to use it."

- "More training around FIT with regards to both inpatient and outpatient treatment for FIT youth and family involvement."
- "Create a greater awareness of FIT, the purpose of FIT, how families initiate and participate in FIT."
- "Educate parents on the clinical aspect of FIT and that it functions as voluntary treatment, therefore, using the same process to request authorization of services."
- "Be clear that this is a voluntary for providers to provide FIT to access care and provide legitimate legal protections for youth that includes the right to attorney representation (not dependent on the minor's ability to pay or their parent's agreeing to pay) which ensures the process also preserves the adolescents rights."
- "These teens should come in through the WISe program with MCO's as the funding source and a requirement of a team approach to services mandating family involvement."
- "Inform clinicians how they can use FIT even if the youth does not participate."
- "It is still not possible to truly have family initiated SUD tx (treatment) due to federal laws. I hope there is some discussion happening around this. Many families are desperate to get their child the SUD treatment they so badly need."
- "I would ask a cadre of young people. Both adolescents and young people who are just beyond that stage developmentally. I believe they may tell us that involuntary outpatient treatment is not likely to be effective. Outpatient tx (treatment) can be very effective once a youth is successfully engaged. FIT would seem to be a better 'fit' when a youth is engaged in dangerous behaviors - e.g. substance use that is significant - and inpatient tx (treatment) is essential. And in our experience, it does not seem to be an effective or needed approach for youth referred for WISe."
- "Treatment centers need enough security to handle FIT admissions as they will be working with "involuntary" patients. Young patients will challenge unit boundaries."
- "Provide more trainings to agencies. I don't know if families are able to follow through with the commitment. I've seen parents who are scared of their kids when they are forced into situations such as these. I've also seen parents who are not willing to argue to force kids into these situations because it disrupts home life. More support to families. I don't see many families who don't have family issues themselves where the kid is the one and only who needs help."

Conclusion

Opportunities for further survey development

The 2020 FIT survey report is the first of three reports required by E2SHB 1874 (2019). HCA is using the data received from the 2020 report as a baseline to understand the impacts of roll out and implementation of FIT, assess policy strengths and needs, and inform the final report and any policy recommendations made in the final report from lessons learned.

Through the review of the 2020 baseline data, opportunities were identified that would inform planning and implementation efforts being done for FIT.

1. **Youth Voice:** The need for an increase in youth voice for future surveys and stakeholder work. The 2020 survey received a maximum of 11 total youth or young adult respondents, with some questions answered by as few as two youth respondents. Ensuring youth and young adult input in advance of the 2021 survey will be a priority to ensure there are a variety of ways for youth to engage in future surveys.
2. **Provider voice**: The need for an increase of inpatient provider voice for future surveys and stakeholder work. For the 2020 report, the largest show of responses was from providers, but from the 137 provider respondents only 14 percent were inpatient providers. Having an inpatient provider voice is essential in understanding the impacts of implementing FIT.
3. **Parent voice**: The need for continued outreach and inclusion of parent voice for future survey and stakeholder work. The 2020 survey received a maximum of 68 parent respondents. Continue to work with parent support networks to ensure broad distribution of FIT advisory opportunities.
4. **Training and education**: The need for continued training and education on what FIT is and implementation strategies for communities and providers. Online training is rolling out this fall for providers, community, and parents on FIT as well as engagement strategies training for clinicians and agencies.

Survey data will be used to inform ongoing training and education opportunities.