PPAL Family Driven Research

Telehealth for Families and Youth - What's Their Take?

Findings from a survey of families, youth and young adults on telehealth during the COVID-19 pandemic

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Executive Summary

When COVID-19 cases began accelerating in the spring of 2020 and stay at home orders were put into place, families had little time to prepare. Although most were unfamiliar with telehealth, they made rapid adjustments in order to access care, including mental health care, for their children. While telehealth was not developed to meet mental health needs during a pandemic, it became a lifeline, sometimes an imperfect one for families, youth and young adults.

In mid-May 2020, Parent/Professional Advocacy League sent out two short surveys, one to parents and another to youth/young adults to hear about their recent experiences with telehealth. Each survey consisted of 21 structured questions and one open ended question. 202 families responded and 151 had used telehealth at least once. 30 young people, ages 13 to 30, responded to the second survey.

The majority of families (91%) who had used telehealth had done so for the first time in the two months prior to taking the survey, or mid-March to mid-May 2020. The largest number reported that their child had had a telehealth visit with an outpatient therapist (39%), a psychiatrist (29%) or with their child’s pediatrician (29%). Similar to the parent responses, 89% of the youth and young adults reported that they had already had a telehealth session with 61% reporting their first visit had been in the previous two months.

Top Findings
Access to internet and devices was problematic for some parents. The large majority of families (76%) reported that they had access to a strong internet signal and another 21% said they had internet access but their signal wasn’t always adequate. While only one parent reported that they had no internet, almost one in ten (7%) of youth said they did not have internet or were unsure if the signal was adequate.

Several parents stated that while their own internet connectivity was fine, the provider’s was not, leading to interruptions in telehealth visits.

Families reported that the device they used most frequently for telehealth visits was a laptop or computer (42%) followed by cell phones (31%) and tablets (12%). However, African American parents reported that they were most likely to use a cell phone (61%)

Apps, especially multiple apps or platforms, created difficulties
Both parents (67%) and youth (89%) reported they needed to download an app before they could access telehealth. Many experienced difficulty and only one-third reported they received
help from the provider. 1 in 5 said they had to download multiple apps for different providers, even in the same agency. Youth found the technology easier but were more critical of providers for their lack of help.

Almost 20% of parents and 29% of youth reported missing one or more appointments because of problems with the apps.

Effectiveness and best uses
62% of families and 59% of youth said that care through telehealth was at least somewhat more effective than face-to-face visits. However, many cited a strong preference for face-to-face visits.

The majority of both parents and youth said the best uses of telehealth are (1) checking in on an ongoing basis, (2) managing an ongoing health or behavioral concern and (3) managing medications and getting prescriptions.

Very few parents (15%) thought telehealth was a good method for delivering care in a crisis, although twice the number of young people (30%) thought otherwise.

Drawbacks to telehealth
Parents said the greatest drawback was that their child lost interest during telehealth visits (42%) followed by worries (41%) that the provider couldn’t see all of the child and missed clues such as a child jiggling their feet or showing other nonverbal cues.

Youth and young adults rated losing interest or focus more than they did in a face to face visit as the top drawback for them (63%). Lack of privacy (41%) was a greater concern for youth and was highlighted by many young people.

Recommendations from Families and Young People

Providers should routinely check in to see how telehealth is working. Providers should ask families and young people for feedback on regular basis to find out how well telehealth is working. Most reported that this has rarely happened.

Providers should help troubleshoot technology issues if they are going to use it. Providers should check whether families have enough devices and a strong enough internet connection (40%). Providers should offer help with setting up apps before the first appointment.

Talk about home distractions and privacy first. There should be a conversation before the first telehealth appointment of whether there is adequate privacy, any concerns about the new
technology and confidentiality or if there is also remote learning going on in their homes leading to competing needs for devices.
Introduction

When COVID-19 cases began accelerating in March 2020, stay at home orders were put into place in many states with little advance notice. Families whose children had behavioral health needs were abruptly told that important care for their children would now be offered remotely. Many were unfamiliar with telehealth and its technology requirements such as specific apps or platforms. Their computers, phones and tablets had already been designated for remote learning for several children now at home and they also had to figure out how to also use them for telehealth.

Some families made the adjustment easily. They had several devices at home so that computers or phones were not a limited commodity. They had a reliable internet signal. They were comfortable with technology and quickly learning new software didn’t increase their stress level overmuch.

Other families found it more difficult. They had fewer devices to share among their children and handing them over often meant they were themselves without a phone. Their internet signal was problematic, especially with so many people in their household now using it all at the same time. Some parents and grandparents (who were raising grandchildren) were flummoxed by learning new software. While many young adults found the technology easy to navigate, others struggled to master it. One mother wrote, “My child just turned 17 and has some learning challenges. The doctor’s office was very short with her when she was unable to comprehend the directions to download the app and set up the first appointment. This caused her anxiety to increase and my frustration to increase and we both ended up in tears. Because she is 17, they would not include me.”

Telehealth was developed decades ago to serve rural populations and is finding a new purpose during the pandemic. Because most people have cameras, data plans and free apps available on their smartphone, it is far easier now to access treatment remotely. Telehealth apps are getting less attention than other forms of social distancing, but they’re turning out to be an
important first line of defense to slow the spread of the coronavirus.\textsuperscript{1} With these factors in place, many assume that both families and youth/young adults coping with mental health challenges would welcome care via telehealth.

Families began swapping stories online about their experiences with telehealth very quickly. Some were enthusiastic, some had reservations. Many found it difficult to change their idea of what it meant to “see” the doctor or therapist. Others embraced the new format but found it lacking. But nearly all were grateful that the care continued, almost without interruption, during the ongoing coronavirus crisis.

Methodology

In May 2020, Parent/Professional Advocacy League (PPAL) sent out a “pop-up survey”\textsuperscript{1} on telehealth to families and others connected to PPAL through its mailing list and social media groups. Families were entering their third month of confinement at home due to the COVID-19 pandemic and coping with remote learning, receiving medical and mental health care via telehealth (often for the first time) and increased demands due to the stay-at-home orders.

A separate pop-up survey for youth and young adults was also posted online. Working with Youth MOVE Massachusetts (YMM), PPAL sent out this survey primarily through its own and YMM’s social media. Survey questions were similar in order to facilitate comparisons between parent and youth/young adult responses. Both surveys were designed to capture the experience of families and youth as well as their opinions and the value they placed on receiving care for through telehealth.

Each survey was available online at surveymonkey.com and was available for 15 days. The surveys for both families and youth/young adults were limited to 21 structured questions and one open-ended question about the experiences they had had using telehealth as well as their opinion of its benefits and drawbacks. At the end of each survey was a link to enter a weekly raffle for an Amazon gift card.

\textsuperscript{1} A pop up survey is similar to pop up shops and restaurants which are temporary and limited in scope or offerings
Demographics

Family survey. A total of 202 people responded to the survey for families. Almost all of the respondents said they were either a parent (85%) or a family member (7%) of a child with needs. 58% of the respondents were parents of a child with behavioral health needs and 6% were parents of a child with special health care needs. Another 21% said their child had both behavioral health and special health care needs. Only 7% said their child did not have special needs.

The majority of respondents (75%) identified as white. Another 14% said they were African American and 6% identified as Hispanic. In addition, 2.5% said they were Asian or Asian American and an additional 2.5% told us they were more than one race.

Three-fourths (71%) of the families had children between 6 and 17 (see chart). Only 5% of the respondents had indicated they were parenting a very young child 5 years or under. An additional 18% had children between 18-21 years. Ten respondents had children over 21 but elected to take the survey because they wanted to contribute their experiences to the data.

The majority of the children were insured by MassHealth (49%). Another 34% had private insurance and an additional 16% had a combination of private insurance and MassHealth. No one reported that their child was uninsured. A small number had other insurance coverage such as military or in one case, out of state Medicaid (this child was living with their grandparent). Parents of very young children (0-5) were more likely to report that their child was covered solely by private insurance (50%) and children who were 15-21 were the largest group to be covered by a combination of private insurance and MassHealth (22%). Children who were Hispanic were the largest group to be covered solely by MassHealth (75%).

Youth/Young adult survey. A total of 30 young people responded to the youth/young adult survey. Young people ranged in age from 13 to 30. The largest group (46%) were between 18
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and 25 years. The majority (83%) were white and 7% identified as Hispanic, more than one race (7%) and American Indian (3%). No respondents identified as African American.

Unlike the survey for families, the largest group (37%) reported that they were covered by private insurance, closely followed by those with MassHealth coverage (30%) or a combination of private insurance and MassHealth (23%). One young person reported that they were uninsured and one was unsure about the type of insurance they had.

Telehealth use

Of the 202 respondents, 151 families reported that their child and family had already had a telehealth visit (parents often participated in the telehealth visit for the child). Of those, 91% had had a telehealth visit for the first time in the 2 months prior to taking the survey or mid-March to mid-May 2020 (see chart). In Massachusetts this coincided with the beginning of the stay at home orders due to COVID-19. Only one person said their child had been receiving telehealth for 6 months or more. An additional 6% of all respondents had a telehealth visit planned in the near future.

When asked what services they had accessed via telehealth (see chart), the majority of families reported that their child had had a telehealth visit with an outpatient therapist (39%) or a psychiatrist (29%) followed closely by a telehealth visit with their child's pediatrician (29%). Of the range of services offered through the Children’s Behavioral Health Initiative (CBHI) (see Appendix A), in-home therapy was most frequently accessed through telehealth (12%) followed by therapeutic mentors (15%) and family partners (11%). Very few families reported that they used telehealth to access intensive care coordination (9%) or mobile crisis (1%).

Higher than the parent responses, 89% of the youth and young adults reported that they had already had a telehealth session and one youth reported that they had one coming up. While
the majority (61%) had received care via telehealth for the first time in the previous two months, 29% reported having telehealth visits for 3-6 months before taking the survey (also higher than reported by families).

Among the range of age groups, parents of young children responded in larger numbers that their telehealth visit had been with a pediatrician (40%). African American families also reported that they had used telehealth most often to access their child’s pediatrician (36%). In a 2018 survey of families, PPAL found that African American families often preferred seeking care, even behavioral health care, for their child from primary care doctors, saying their opinions and culture were more respected by them than a therapist. They also reported that they were more likely to be included in decision making. Parents of transition age youth (18-21) reported that tele-visits with a psychiatrist was most the often used (40%) care.

Half (53%) of the young people had seen their primary care doctor via telehealth, 63% had seen a therapist and 56% had seen a psychiatrist. In addition, 17% had seen a medical specialist. The respondents reported that they were familiar with medical and mental health visits and were able to use these experiences to compare with telehealth experience.
Insurance coverage, internet and devices

No parent reported that their insurer created any barriers to receiving care for their child through telehealth. 75% of the families reported that they were aware that their insurance covered care via telehealth while 25% were unsure. Looking at insurance type, MassHealth families (79%) and families whose children were covered by a combination of private insurance and MassHealth (84%) were significantly more likely to be certain that their child’s insurance covered telehealth visits compared to those covered by private insurance (68%).

Far more young people (37%) were unsure if their insurance covered telehealth visits than parents were. 57% were certain that telehealth care was covered and 7% reported that it was not covered. This includes the young people who were uninsured.

Participating in telehealth visits requires an adequate internet signal. The large majority of families (76%) reported that they had access to a strong internet signal and another 21% said they had internet access but their signal wasn’t always adequate. Only one respondent replied that they didn’t have access to the internet and 2% were unsure. This included families planning a telehealth visit who had not already had one. Hispanic families were the twice as likely to report that their internet signal was not strong enough at times (44%).

Several parents stated that while their own internet connectivity was fine, the provider’s was not. One said the provider’s internet connection faded in and out and another complained that her son’s telephone appointments were interrupted by the provider’s phone being disconnected multiple times by other calls. Another parent wrote that “the quality of the app impacts our ability to understand the provider. When there are glitches…it is hard to understand important information they are providing. It also frustrates my children and causes them to not want to participate in the meeting anymore or to get upset.”

“I filled this out specifically about my 18-year old’s ADHD medication management visit, but we also had a positive experience with my 11-year old’s pediatrician able to diagnose and prescribe meds for an ear infection.” – a parent

“It can be difficult when their [the provider’s] reception isn’t great, as it takes something that’s supposed to be helpful like therapy and makes it more stressful at times.”
Families reported that the device they used most frequently for telehealth visits was a laptop or computer (42%) followed by cell phones (31%) and tablets (12%). Only African American parents reported that they were most likely to use a cell phone (61%). One parent remarked, “With only one phone for telehealth, this is not an optimal method for single parent households.” Another said, “My child has to use my phone and reads my incoming messages.”

While only one parent reported that they had no internet, almost one in ten (7%) of youth said they did not have internet or were unsure if the signal was adequate. Fewer youth (61%) were confident that their internet signal was fine and 29% identified that their signal was not strong enough at times. Youth answers were similar to those of parents when they identified the device they used for telehealth visits: 43% used a computer or laptop, 32% used cell phones and 11% reported using a tablet.

Apps and difficulties

Most families (67%) reported that they had to download an app before they could have a telehealth visit. Many experienced some difficulty. One wrote, “I wasn’t told I had to wait until 10 minutes before the appointment to have access to it.” Less than half (48%) said it was fairly easy to download the app while 20% already had the app on their laptop or phone. Families of younger children were less likely to report that it was complicated. 19% said they had to download more than one app, even if they used different providers within the same agency, hospital or health care system. A mother commented that, “One platform should be used by the same agency. Why are there multiple platforms within just one agency, IHT, outpatient, therapeutic mentor and psychiatry all with different platforms? They are all from the same agency – why on earth do you need multiple apps?”

When asked if they received help with the app or technology needed to access telehealth, one in three (34%) reported that they received no help. 10% told us they got an email before the first telehealth visit but found that it wasn’t very helpful. As a result, one in five (19%)
reported that their child missed one or more visits because of problems with the needed app (see chart). The parent of one child said, “Not all families will be able to read the instructions attached to the emails for a first telehealth visit. A phone follow-up with a family is needed to set up the initial visit. Technology is intimidating for some.”

Youth also reported having to download an app (89%) before they could access telehealth. One in ten (11%) said they already had the needed app. Youth found it far easier to navigate the technology than parents did. 61% reported that it was easy to download the app while 11% found it was complicated. As with parents, 18% said they had to download more than one app to access telehealth with different providers. 4% said they didn’t have room to download the needed app.

However, young people were more critical of the help (or lack of it) offered by providers (see chart). Twice the number of youth (21%) as parents found the email with instructions on accessing telehealth from the provider not helpful and three times the number of youth said the provider didn’t offer help with the app. A recent survey by IT vendor Sykes of 2,000 adults throughout the US found that while younger people were more receptive to using telehealth, those who live in the Western US are the most likely to have been informed on how to use telehealth services. iii This lack of information was pointed out in comments by several young adults.

Almost one-third (29%) of youth also said they missed one or more appointments because of difficulties with the required app. This was higher than parents reported. One youth wrote of the process, “I would like for it to work better.”

Medications and telehealth

When asked whether their child took prescribed medication, 65% reported that their child took medication for a variety of behavioral health needs including ADHD, difficulties with mood or
outbursts. 25% of the children also took medication for sleep issues. Another 23% were being treated with medication for medical concerns. 20% reported that their child took no medication while 10% said their child had taken medication in the past but does not now (see chart). Parents whose children had only private insurance were more likely to report that their child was not taking medication at this time but 33% more likely to say their child has taken medication in the past.

Overall, 48% reported that they had been able to get prescriptions, either for a new medication or a refill, using a telehealth visit. An additional 42% said they had not needed to yet and only 8% said they were unable to do this. Parents of children 12-17 were most likely to have used telehealth to access prescriptions for medications (55%).

Families covered by MassHealth (48%) or with MassHealth secondary (48%) were more likely to have used telehealth for prescriptions compared with those with private insurance (38%). Families covered by private insurance were also more likely to report they had not yet needed to get a prescription or renew one (55%).

When asked about the prescribed medications they take, youth answers were nearly identical answers to those of parents. 67% reported taking medications for a variety of behavioral health needs including ADHD, difficulties with mood or outbursts. Almost a third (30%) also took medication for sleep issues and 20% were being treated with medication for medical concerns.

The percentage of young people who reported that they were able to get prescriptions (64%) via telehealth was somewhat higher than in the survey for families. Fewer youth/young adults (25%) reported that they had not needed to get a prescription or renew one when they took the survey.
Benefits of using telehealth

When parents were asked about the top benefits of telehealth, almost three quarters (72%) said it was not having to travel or get their child into the car or on transportation. One parent described telehealth as an “incredible time and hassle saver. No pre-visit intensity from my son.” 82% of young people agreed that not having to travel was the top benefit. Parents also cited the flexibility in appointment times (58%) as did youth (45%). One parent wrote, “This is a game changer for us in such a positive way. Not having to drive for hours in traffic, not having to pull my child out of school for an appointment. Being able to talk to the doctor with my child safely in another room.”

Some parents said not having to worry about germs or catching the virus as they would in a face-to-face visit during the pandemic (58%) was also a significant benefit for them. Only parents of children under five selected not worrying about germs/catching the virus as their top priority (78%). Youth also chimed in to say that not worrying about germs was an important advantage in telehealth care (41%).

One third (33%) of the parents noted that they had shorter wait times for care with telehealth, although this may be a result of other factors as well. Parents pointed out that they thought that the provider could see the child “just as they are” instead of “being good” for an office visit (22%) but young people didn’t agree that this was especially beneficial (7%).

Parents felt strongly that the three best uses of telehealth for their child were

- consulting and checking in on an ongoing basis (61%)
- managing an ongoing health or behavioral concern (60%)
- managing medications and getting prescriptions (52%)

Very few parents (15%) thought telehealth was a good method for delivering care in a crisis or responding (23%) quickly to sudden symptoms or situations and few reported using mobile crisis.
services. One parent wrote, “Telehealth helps with things that need minimal attention, like a check in or medication check. I wouldn’t like to see in place of face to face.” Another disagreed and told us, “I like it very much. And I would like to continue to use it.”

Youth and young adults echoed the parent respondents on the best uses for telehealth, choosing as the top benefits:

- consulting and checking in on an ongoing basis (48%)
- managing medications (48%)
- managing an ongoing health or behavioral health issue (41%)

Young people, however, rated the use of telehealth for deciding what to do in a crisis somewhat higher (30%) although one commented, “It has some obstacles.”

**Using telehealth on an ongoing basis**

When asked if they would like to continue using telehealth for their child after the health concerns about COVID-19 have diminished, there was not an overwhelming endorsement of telehealth. Many (43%) said they would like to continue to have psychiatry and medication management via telehealth. 38% also said they would like to continue outpatient therapy via telehealth. Only one-third (32%) agreed that they would want to continue their child’s visit to their pediatrician or primary care doctor using telehealth and 15% said that they would like to continue speech therapy. This did not vary by insurance coverage or race/ethnicity of the parent. One parent commented, “Although it has its advantages, I believe in person is more effective, especially for therapy vs. quick med checks.” Fewer than 10% indicated they would be interested in accessing any other service on an ongoing basis, including CBHI services, via telehealth after the pandemic had abated. One parent wrote, “Telehealth should be an option for selected visits. However, I don’t believe they take the place of in person visits.”

Parents of children under 11 years, were more enthusiastic about continuing visits to their child’s pediatrician via telehealth (51%) than parents of other age groups. Interestingly, 34% of all parents said they would like to continue to attend support groups virtually.

Young people also weighed in. Similar to the parent responses, many said they would like to continue with psychiatry appointments (44%) and nurse or nurse practitioner visits (22%) via telehealth. Less than a quarter (22%) wanted to continue outpatient therapy visits through telehealth. One young person commented, “I like telehealth for my psychiatrist because we don’t have to travel an hour in the car to see him, but I like in person with my therapist better.”
One worry was the reinstatement of insurance co-pays. One parent noted, “Most insurances are not charging copays for telehealth visits. Copays can be big deterrent to getting services.” Youth, too, expressed concern. One wrote, “My insurance only covers telehealth now during COVID-19 and has waived all copays for mental health services.”

**Effectiveness**

The desire to limit telehealth to certain kinds of care was not due to perception of its effectiveness. When families who had already experienced telehealth visits were asked to rate the effectiveness of telehealth compared to face to face visits, a majority (62%) said that it works better or somewhat better for their child and family (see chart). One parent wrote, “I love telehealth overall and would like to increase its use and effectiveness.”

Which means that one-third (35%) felt that it was somewhat or much worse for their family overall. Only 13% reported that the effectiveness was pretty much the same as in person visits. Another parent commented, “It should not replace face to face meetings.”

Young people were similarly positive when rating the effectiveness of telehealth (see chart). Most (59%) said it was better or somewhat better for them overall, while less than one-third (30%) said it was worse or somewhat worse for them. One said flat out, “I just don’t like it” while another felt differently saying, “I hope telehealth appointments stay.”
Drawbacks to telehealth

When asked what the drawbacks of telehealth were, parents were most concerned that they observed that their children lost interest in the visit more than they did in face to face visits (42%). This was considered the largest drawback for children who were 14 and younger, and was reported by parents as the second largest concern for older youth ages 15-21. The next largest concern (41%) was that the provider couldn’t see all of the child and missed clues such as a child jiggling their feet or showing other nonverbal cues. This was the top worry for Hispanic families. Some families have also reported that their child has concerning behaviors such as picking at their skin, even causing bleeding, which is worsening during the stay at home period and is not seen or known by the provider unless the parent points it out separately.

These worries were followed by concerns that there is a lot going on at home which could be distracting or even chaotic (36%) and the environment was not conducive to some visits. Parents also noticed that their children had a more difficult time being still for the entire appointment at home (30%). Many children are accustomed to moving around and turning their heads instead of staying still looking at a screen.

Several parents said their child refused telehealth therapy entirely. One mother said that her child “is extremely self-conscious about seeing himself on a screen and so far has refused all telehealth appointments with his therapists.” Another said her daughter found it more awkward to share her feelings over a screen. One parent worried, “We are sacrificing quality for flexibility. Anything is better than nothing, but telehealth is no replacement for an in person therapy session.”

One in 10 parents (9%) said there was no downside at all to telehealth. One wrote, “I like it very much. And I would like to continue to use it.”
Youth and young adults had similar observations and rated losing interest or focus more than they did in a face to face visit as the top drawback for them (63%). They also noted that the provider couldn’t see them and they had to spell things out (33%). One remarked that it is more tiring (emotionally) to do video calls than in person visits. Lack of privacy (41%) was a greater concern for youth and was highlighted by many young people. As one commented, “The safety of her office is not there. To discuss traumas that happened at home from home is scary and makes me not really say fully what I feel. I kinda feel like the appointment time was not well used.”

Family and Youth Recommendations

Providers should routinely check in to see how telehealth is working. The top recommendation from parents (52%) was that providers should ask them for feedback on regular basis to find out how well telehealth is working for their child and family. Most reported that this has rarely happened.

Providers should help troubleshoot technology issues if they are going to use it. They also advised that providers should check whether families have enough devices and a strong enough internet connection (40%). As the summer begins, many parents have been required by their school districts to return tablets they had used for both remote learning and telehealth, leaving them trying to figure out how to access telehealth care without them. Almost half (42%) also felt strongly that their child’s provider should offer help – other than a standard email – with setting up apps before the first appointment.

Talk about home distractions and privacy first. Additionally, more than a third (34%) said that there should be a conversation about the home situation before the first telehealth
appointment. Families found themselves having their first appointment without a discussion of whether they were able to talk privately, whether they had concerns about the new technology and confidentiality or if there was also remote learning going on in their homes leading to competing needs for devices. One mother said that her son’s therapist “contacted an old friend who works for Zoom to get a cheat sheet on how to ensure confidentiality.” She worried that there isn’t true security with telehealth and providers should “not just keep telling people it’s okay, it’s confidential.” Instead, she said parents should be made aware of any risks.

The top recommendation by youth (63%) was also that providers should regularly ask for feedback on how telehealth is working. Nearly half of young people (48%), a far larger group than in the parent survey, thought that providers should have a conversation with them about their home situation before the first appointment. And they stressed that conversation must include whether there is adequate privacy. One remarked that “telehealth is good for use occasionally or for when it’s hard to have in person visits. I prefer those.”

“Thanks for this option in this crisis time. I hope we can get back to face to face humanity soon.” – Young adult
Appendix A – Services Accessed for Children via Telehealth

List of Services Accessed through Telehealth

- Substance use professional
- Mobile crisis
- Occupational therapy
- Speech therapy
- Intensive care coordination
- Medical specialist
- In-home Behavioral/ABA
- Support Groups
- Family Partner
- Nurse or NP
- Therapeutic mentor
- In-home therapy
- Primary care doctor
- Psychiatrist
- Outpatient therapy

Youth vs. Families
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