THE TOP 10 THINGS I WISH I'D KNOWN ON MY CHILD'S MENTAL HEALTH JOURNEY

Mensana
Learning + Systems Change

BY: DR.JENNIFER ULIE

FROM ONE PARENT TO ANOTHER

Dear Parent or Caregiver,

My name is Jen, and if you're reading this letter, it's likely because you're concerned about your child's mental health or have been navigating the complexities of this journey for some time. Regardless of where you stand in this path, this toolkit is crafted with you in mind.

With over two decades of experience in youth and school mental health, I bring a wealth of knowledge and understanding to this area. However, the most profound and impactful experience I possess comes from my personal journey as a mother of a child with complex mental health needs.

Raising a child with such needs is an immense challenge. Rarely was I offered resources, guidance, or support, which made our journey significantly more difficult. It's this very lack of readily available help that inspired me to create this toolkit.

My intention is to provide a robust starting point for parents like you, who are also navigating the sometimes-turbulent waters of raising a child with mental health issues.

You may have received this toolkit from your child's doctor, their school, crisis services, a friend, or you might have discovered it on your own. Regardless of how it came into your hands, I am genuinely glad it did. This resource is meant to be a beacon of hope and guidance in times of need and uncertainty. Please keep it handy for future reference.

Remember, you are not alone in this journey. Together, we can strive for a better understanding and a more supportive environment for our children.

With warm regards and solidarity,

Jen

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BY JENNIFER ULIE, PHD

One summer, my child experienced multiple suicide attempts, which led to seizures and a cascade of complex health needs. I've come to refer to it as the "hardest year of my life." It wasn't solely the severity of my child's needs that made it feel so unbearable, it was the culmination of nearly two decades of missed opportunities and the stark realization that, even in our darkest hours, we were alone, without a guiding hand or a source of comprehensive help.

As a professional in youth mental health, I felt a profound sense of incompetence. Despite my deep passion and relentless efforts, I found myself unable to secure the necessary resources and support. I had founded a youth mental health nonprofit, impacted thousands, yet there I was, feeling like I was failing both my son and myself.

My work took a backseat as I spent countless hours on the phone, reaching out across the nation, pleading with anyone who'd listen for help and guidance. In the most critical hospitalization, we were shuffled between five different hospitals, each unable to fully address the complex interplay of my child's behavioral and medical needs. Even our state's leading research hospital admitted his needs were beyond their capabilities.

The bitter irony was that every professional we encountered seemed to pass the buck, yet not one offered us a lifeline or pointed us toward further assistance. It was only after I penned desperate letters to hospital administrations that any additional resources were offered, and even then, it was weeks later.

The aftermath left me grappling with Post Traumatic Stress Disorder, oscillating between two overwhelming emotions: rage and devastation. I wasn't just angry. I was incandescent with rage, often alone due to the trauma of the situation.

The constant state of survival mode led to the shutdown of my brain's prefrontal cortex, the center of rational thought and decision-making. I was emotional, furious, tearful, and merely trying to survive. For parents of children with complex needs, this mode of constant vigilance never truly turns off.

Despite the chaos, I was acutely aware of the privileges I held as a well-educated, well-connected, middle-class white mother. Knowing that my ordeal was daunting, I couldn't help but think of the catastrophic experiences of less privileged individuals. I vowed then that our suffering would not be in vain. I felt a profound obligation to ensure no other family endured what we did.

While systemic change is desperately needed, I knew we couldn't afford to wait. So, here we are.

From a mother who never imagined her once squirrely and sweet six-year-old would face such tribulations as an adolescent, I wish to share the lessons I've learned, the opportunities I wish had been presented to me, and the essential navigation tips that might not have prevented our situation but would have undoubtedly eased our journey.

If you suspect even a mild concern about your child's mental health, please hold onto this list. You might not be ready to tackle it just yet, but if you're reading this, it means you're aware, and awareness is the first step. As a mother who was once not ready to face these realities, I implore you to save this list.

1.COLLECT EVERYTHING

I desperately wish someone would have told me this when my children were very young. Collect every report, test, document you get regarding your child and put it in a safe place. How you collect it doesn't matter as much as you putting them in a safe spot.

My sister-in-law operates like a precision instrument, with everything neatly color-coded and tabbed. My approach, however, is more freeform – if I manage to get everything into a folder, I consider it a victory. Even kids without mental health concerns come with a heap of school and medical paperwork, like standardized test results and immunization records.

Early on, I underestimated the importance of having these documents at hand, so my casual system of piling them on the kitchen counter simply didn't cut it when I needed them urgently.

My advice? Opt for a physical folder tucked in a drawer and a digital folder in your cloud drive (ensuring it's cloud-based for access anywhere). As you receive documents, promptly toss them into these designated spots. Believe me, when the time comes, you'll be thankful you did.

2.TRACKING YOUR CONCERNS

I personally lean towards a digital journal, but you'll find plenty of paper and pencil methods as well. It's crucial to monitor not only the concerning behaviors and shifts in mood but also elements like sleep, diet, exercise, and screen time. This practice is vital for a few key reasons.

First, in the relentless pace of daily life, it's all too easy to lose track of the specifics - what happened and when. Our minds tend to hold a general impression of how frequently certain events occur, but jotting them down provides a grounded and accurate view.

Moreover, this documented data is incredibly useful for spotting patterns and triggers that might be influencing behaviors or emotional changes.

For instance, if a night of poor sleep leads to a day of difficult behavior, focusing on improving sleep could be a game-changer.

Most importantly, if your experiences mirror mine, discussing your concerns effectively with a doctor can be daunting. Having a comprehensive log empowers you to present clear, detailed information to medical and mental health professionals. This ensures they gain a more precise understanding of your child's situation, leading to more accurate diagnoses and treatments.

3. EARLY INTERVENTION IS KEY & YOU AREN'T FAILING AS A PARENT

My child first started showing symptoms as an infant. I had no clue at the time that's what I was seeing, I assumed it was just colic. As a toddler, everyone says to do timeouts but when we did timeouts it was an all out battle to go and stay in timeout. I read every book I could find and scoffed that they clearly had not met my child because the strategies were not designed for how his brain was wired. At that point, I wish I would have pushed more with the pediatrician.

When we did see the doc, I think shame and guilt had me minimizing what I was seeing when we saw the doctor. I thought the behaviors were a result of something I wasn't doing right. My family and friends all had an opinion (insert eye roll here) that usually involved thoughts on how I should be discipling, dietary choices, tv time, but what they didn't know was that my child had become my other full-time job and I WAS trying everything.

Had I been more upfront, shown up with my journal of what I was seeing, and pushed more with the doctor, we may have found out my child had Autism Spectrum Disorder earlier and started services a decade sooner. Note: Autism is a developmental disability versus a mental health diagnosis yet often they can coexist.

If you're reading this and you're in a place where you wonder if something related to mental health is going on with your child but you think it could also be other things that's completely fair. Raising children is truly a journey and they do not come with manuals.

Here's my best advice: If you are concerned, take them to your pediatrician for an honest conversation about what you're seeing. I would ask for bloodwork to evaluate anything that could be mimicking your concerns such as a vitamin deficiency.

Unfortunately, mental health is so stigmatized that we as parents are conditioned into feeling like we have failed or something is "wrong" with our children if they have a mental health diagnosis or treatment. If your child had asthma would you be beating yourself up as a parent? If your child had juvenile diabetes would you be feeling like they just aren't trying hard enough to do what they were supposed to be doing?

Remember mental health is a biological, medical condition. They do not choose this anymore than they would choose asthma or diabetes. If they need medical treatment, the best gift you can give them as a parent is getting it for them sooner than later. Research continues to mount that early intervention can drastically improve long term outcomes.

I spent a long time seeped in blame and guilt. I made countless excuses for what I was seeing until I ran out of excuses. I don't hold any regret for our journey but if I could do it again I would have agreed to meds earlier, pushed for more support, programs, and resources.

4. CONSIDER PURSUING A NEUROPSYCHOLOGICAL OR PSYCHOLOGICAL EVALUATION

Despite my professional background in youth mental health, navigating my own child's needs often left me feeling surprisingly out of my depth. Chronic stress can push our brains into survival mode, shutting down the prefrontal cortex – the very part responsible for executive functions, rational thought, and decision-making. I could dispense sound advice to other parents effortlessly, but when it came to applying that wisdom to my own situation, my emotional turmoil, guilt, and shame often clouded my judgment.

For years, I've advised parents on the importance of obtaining neuropsychological or psychological evaluations for their children, yet found myself hesitant to do the same for mine. The weight of guilt and shame, the nagging feeling that I might be responsible for my child's struggles, often led to avoidance and a silent hope that the issues would simply resolve themselves. However, everything changed when my eight-year-old child, already under treatment with antidepressants and therapy, threatened suicide.

At that critical juncture, the severity of the situation became undeniable. During hospitalization, we discovered that the prescribed antidepressant was inducing mania. A thorough psychological evaluation, coupled with a change in medication, significantly improved the situation for an extended period.

To clarify, a psychological evaluation, typically conducted by a psychiatrist or psychologist, assesses an individual for various mental health conditions and developmental disorders, including but not limited to depression, anxiety, bipolar disorder, Autism, and substance abuse. A neuropsychological evaluation, while similar, includes specialized tests that also assess intellectual, cognitive, sensory processing, language, executive functioning, and learning disabilities, among others.

Depending on your state, your child might be eligible for a neuropsychological or psychological evaluation through their school. These assessments require your consent and can pave the way for additional support services and accommodations to help your child thrive academically.

While school psychologists and private neuropsychologists are invaluable resources, if you suspect your child has more complex needs, I strongly recommend seeking an evaluation from a university medical research hospital. After my child's suicide attempt, we sought help from a private neuropsychologist who was excellent in diagnosing certain processing issues but lacked the nuanced tests needed to identify Autism, which was only diagnosed nearly a decade through a comprehensive neuropsychological evaluation by a university research hospital. If I could do it again, I would have taken my child as a toddler and then a couple of other times to be evaluated as needs change with age.

5. BEHAVIORS NEED SKILL INSTRUCTION

When it comes to my child's behavioral issues, they typically stem from a desire to avoid something or an attempt to gain something, often due to a lack of necessary skills or unmet needs.

Reflecting on my journey, one of the most critical yet overlooked aspects I wish I had addressed earlier is the provision or creation of opportunities for developing social skills. Accessibility to such resources can vary significantly depending on your location, but thankfully, technology is increasingly bridging these gaps.

There have been instances where my child resisted challenging situations, like group work at school. As a well-intentioned parent, I might contact the school to express my concerns and request a different group for my child. However, what I might not realize is that my child's struggle with the group project could stem from underdeveloped social and emotional skills.

They might be overly dominant or excessively timid in conversations, avoid social interactions, lack problem-solving abilities, have poor communication skills, low stress tolerance, or an absence of effective stress management techniques.

While requesting a group change might provide immediate relief, it inadvertently deprives my child of valuable opportunities to develop essential social skills.

It's akin to my experience of returning to the gym after a long break and feeling discomfort. Choosing to stop going would only hinder my progress, just as denying our children the chance to learn and practice social skills does them a disservice.

It's important to differentiate this from situations where my child faces physical aggression or threats from others. In such cases, intervention is necessary to ensure their safety and well-being. But in the broader context, fostering an environment where they can regularly engage in and learn from social interactions is crucial for their development.

Parents and teachers can feel intimidated by explicitly teaching these social skills to our children because most of us never were taught them either. I have to remind myself when I'm training large groups of adults that they also require some explicit instruction on optimizing collaboration, effective communication, and problem solving. It's a misnomer to assume that adults are any better than children in their own emotional intelligence, but it is even more reason for all of us to spend more time with social emotional teaching and learning.

To teach your child a social emotional skill, decide on one specific target behavior you want to see improvement, because it is unrealistic to try to conquer multiple at the same time. After you identify your target behavior, decide what you want to see your child do instead of the undesired behavior. For instance, if your child is impulsive and can overreact in situations, just telling them to behave is way too abstract and does not give them the roadmap of what you want them to do. Remember we need to be very explicit and concrete. For a child that is impulsive and overreacts an appropriate replacement behavior may be to teach them to take a break when they feel their body getting overwhelmed, anxious or angry. Another replacement behavior could be to teach them mindfulness techniques to get a calm body.

When teaching social and emotional skills, explain what the appropriate behavior looks like, then physically model and act out what it looks like, then ask them to practice over and over again. Each time they do it in practice, I want you to make a big deal about how well they are doing it. That praise is called reinforcement. If we want to see a change we HAVE to use high levels of reinforcement.

For those right now, saying "I don't think I should have to reinforce my kid for doing what they should have been doing in the first place," two thoughts. First, you could yell at me until you were blue in the face but if you didn't teach me the Quadratic Formula I wasn't going to learn it. Social and emotional skills that need to be taught as much as math, science, writing or reading.

Second thought... would you go to work every day if you didn't get a paycheck? Reinforcement means we have motivation to do well. Your child wants to please you and needs to feel more success than not to see a change.

Fortunately, there are also a ton of social emotional games, activities, and tech apps available online and in stores to use.

6. EXPLORE A 504 PLAN OR AN INDIVIDUALIZED EDUCATION PLAN (IEP)

Should you suspect your child has a disability, it's within your rights to request an evaluation for special education services. I'm well aware of the apprehensions surrounding special education; concerns are valid, but the potential benefits can significantly alter the trajectory of our children's educational experiences, shifting from aversion to success.

Many parents, perhaps influenced by their own less-than-positive experiences, approach special education with caution. However, just as you wouldn't send your child to school amidst an asthma attack without the necessary medication and accommodations, it's equally vital to address their academic and behavioral struggles with appropriate support.

Mental health and disabilities are often shrouded in stigma, a reality that can clash dramatically with the idyllic expectations we hold for our children's lives. Coming to terms with the fact that your child's journey might diverge from your dreams can be a process filled with grief, guilt, and shame. If you're grappling with these emotions, know that you're not alone.

Even with my PhD in special education, I initially resisted seeking services for my child. It wasn't the fear of labeling or standing out that held me back, but rather a misplaced confidence in my own capabilities. In hindsight, I realize that my reluctance was more about me than my child's needs.

If your child has a mental health diagnosis, they may be eligible for a 504 Plan. This plan can provide accommodations like extended test time, permission for breaks, or access to snacks, which can be surprisingly transformative. To initiate this process, contact the school to discuss with the 504 coordinator, often a school counselor or administrator.

During the initial meeting, express your concerns and needs to help shape the 504 Plan, which should be reviewed and updated annually. Ensure you're informed about when and how the plan will be communicated to your child's teachers at the start of each school year.

For children whose needs extend beyond what a 504 Plan can provide, reach out to a school administrator with your concerns. You might say, "I have concerns about my child's social, emotional, and mental health. I suspect my child has a disability and through Child Find, I am requesting an evaluation for special education services."

Following your request, the school will contact you to arrange a meeting and obtain written consent to begin the evaluation process, which should be completed within 60 days of your consent. After the evaluation, another meeting will discuss the findings, determine eligibility for special education services, and outline the next steps.

7. NOT ALL THERAPISTS ARE CREATED ALIKE

During Covid, people started to pay attention to mental health more, though, mental health has been an ignored epidemic long before the pandemic began. While it's encouraging to see a movement to increase mental health professionals, we have to be cautious in remembering quality > quantity. Simply having more therapists available isn't the solution to the intricate challenges many families face. The heart of effective therapy lies in a therapist's skills, training, and the breadth and depth of their experience with specific diagnoses and behaviors.

As parents and caregivers, our aim shouldn't just be to find "a therapist," but to find "the right therapist" for our child and family.
Choosing a therapist or medication provider is not a unilateral decision but a collaborative one. This choice should be made in tandem with your child, for they are the ones who need to develop a strong connection with the professional.

Their comfort, trust, and willingness to engage are paramount. This journey, while daunting, can be approached systematically in three thoughtful steps:

1.**Research Ahead of Time:** Websites like Psychology Today offer a treasure trove of information about potential therapists, from their credentials and areas of expertise to their personal philosophies and approaches. Moreover, this platform usually showcases a photograph of the therapist, giving you and your child a first glimpse into the face behind the name. It also provides links to their personal websites and contact details, serving as a comprehensive starting point in your search.

2. **Scrutinize Reviews with a Discerning Eye:** Once you have a shortlist, Google their names. Dive into reviews, not just skimming the surface but critically analyzing feedback. Remember, a perfect score isn't necessarily what you're after.

Therapeutic relationships are deeply personal, and what works for one individual might not work for another. However, consistent negative feedback or alarming patterns in reviews — especially pertaining to working with children and families with complex needs — should serve as red flags.

3. **The 'Meet and Greet' Interview:** This step is essential. Before diving into therapy, request a preliminary meeting with the therapist, where both you and your child can discuss your needs, concerns, and expectations. This is an invaluable opportunity to gauge the compatibility between the therapist and your child, and for the therapist to evaluate if they are equipped to support your unique needs. It's absolutely acceptable to conclude that a therapist might not be the right fit. A genuine professional will appreciate the upfront approach, understanding that the ultimate goal is the well-being of the child.

Here are some questions to consider researching and asking as you make your decisions:

Background and Expertise

- What are your credentials and licenses?
- How many years have you been practicing?
- What specific training or expertise in child and adolescent mental health?
- What types of mental health issues do you typically treat in children?
- How comfortable do you feel with families and children having complex mental health needs?

Approach and Treatment Modalities:

- How do you assess & determine which treatment is most appropriate?
- How do you approach treatment for children?
- What evidence-based practices do you use?
- How do you stay updated with the latest research and methodologies in child mental health?

Engaging the Child and Family:

- How do you build trust and rapport with children?
- How do you involve parents and caregivers in the treatment process?
- How often do you recommend family sessions?

Logistics and Practicalities:

- How frequently are sessions typically scheduled?
- What is the expected duration of treatment?
- How do you handle cancellations or rescheduling?
- What are your fees, & do you accept insurance or offer a sliding scale?

Measuring Progress:

- How do you evaluate a child's progress and how often is it evaluated?
- How often do you reassess treatment goals?
- How do you communicate progress to parents?

Collaboration and Integration:

- Are you open to working collaboratively with other professionals involved in my child's care, like teachers, pediatricians, or other therapists?
- How do you approach multi-disciplinary treatments, if required?
- Are you able to provide us with other community resources as needed to help supplement treatment goals such as therapeutic or skill building programs?

8. USE YOUR INSURANCE/MEDICAID COMPANY AS A RESOURCE

The summer my child attempted multiple times, I found myself in an emotional trap that oscillated between rage and devastation on top of fear, exhaustion, and complete desperation. What does a family do when all of the major resources in the state say they cannot help but offer no direction? The parent has to figure it out.

I am eternally grateful to a friend who directed me to a national navigator, who in turn educated me on securing a case manager through our insurance company. This case manager has been an absolute game-changer.

She connected us to an outstanding treatment facility, and she's become such an integral part of our lives that I half-jokingly consider her my new best friend. She's always there when we're exploring new resources and treatment options. I only wish I had known about this support system much earlier.

You have the right to reach out to your insurance or Medicaid company's customer service at any time for basic information. They can assign a case manager to you who will guide you through more complex needs, helping you find intensive resources, be it residential treatment or substance abuse programs.

The process of getting a case manager varies with each insurance company, but typically, your child needs to be identified as having increased needs. Start by calling the customer service line. Detail your child's needs and the difficulties you're facing in accessing support, and express your desire for a case manager. They'll walk you through their specific process, ask further questions, and lay out the next steps for you.

9. YOU HAVE TO TAKE CARE OF YOURSELF

I have learned the brutally hard way that if I do not prioritize my own wellness then I am not good to anyone else including my children.

Raising a child with complex needs wasn't the only catalyst for my health plummeting but it was one of the many things that I thought I was making a priority as I gradually lost myself and my health. I gained 60 pounds, wasn't sleeping, my bloodwork was skyrocketing in all of the wrong ways, I was irritable, and felt like a complete shell of myself. I was no good to anyone because I wasn't being good to myself.

Parenting a child with mental health needs can be incredibly rewarding but equally challenging. Remember to seek support for yourself, be it in the form of support groups, therapy, or simply talking to friends and family. Your well-being is integral to your child's success.

I have come to understand that taking care of myself isn't an act of luxury but a necessity. It is akin to the instruction given on an airplane to put on your own oxygen mask before helping others. I need to ensure that my cup is filled so I can tend to my child's needs from a place of strength, patience, and resilience.

If you are a parent or caregiver, you know that these little people count on you for everything from unconditional love to survival and everything in between. I do not have the luxury of tapping into parenthood when it's convenient, and quite honestly, rarely do things happen at convenient moments.

We are like batteries that only have so much energy to give and when things are in overdrive we are zapped of our energy twice as quickly.

Also like batteries we need ample time and space to recharge ideally not while being zapped of our energy at the same time. We can also do damage to our batteries when we are consistently trying to take energy when there is nothing left to take.

10. YOU AREN'T IN THIS ALONE

You don't have to journey through your child's mental health challenges alone. While I may not hold all the answers, my commitment and experience in the field empower me to assist you in uncovering them. In these trying times, remember that support, understanding, and a caring community are within your reach.

I've learned that the path forward isn't about having perfect solutions—it's about having the right tools, the right support, and the courage to take one step at a time. Every child's journey is different, but no parent should have to navigate it in isolation.

That's why I created ThriveEd. Not because I had all the answers, but because I knew our children deserved something better than the fragmented, overwhelming system we were trying to navigate. They deserved resources that actually worked for families, not just institutions.

If you're reading this and feeling overwhelmed, know that you're already doing something right—you're seeking help, you're asking questions, and you're refusing to give up on your child. That matters more than you know.

The tools exist. The community is here. And your child's story is still being written.

You've got this. And when you don't, we've got you.

Mensana

Learning + Systems Change

YOU ARE

enough.

NEED MORE?

- Podcasts
- Tools
- Webinars
- Digital Downloads
- Resources

"MyMensana" draws its name from the Latin "mens sana in corpore sano" – a healthy mind in a healthy body.

“MyMensana completely changed how my daughter talks about her feelings. She went from shutting down after school to actually telling me what's going on.”

Parent in Los Angeles