Response 1:

Dear Chairman Wyden,

As a primary care physician, I treat mental illness every day. As a wife who witnessed her husband descend into severe depression and suicidality, then experience his first hypomanic episode due to a medication I commonly prescribe, I have a unique perspective on issues surrounding mental illness.

Community resources, rapid response by professionals trained in severe mental illness, and robust research are key. De-stigmatization is imperative to address this epidemic of mental illness that will outlast the pandemic of our time.

I understood the system, had every advantage as a healthcare provider and still my husband, who had no history of severe mental illness prior to 2016, very nearly died several times. I was unable to get him in to see a psychiatrist though it was clear he had suicidal intent. I was told by the social worker on the phone to get "everything sharp" out of the house, try to keep him safe. We had three children, all five and under, at that time. The way we currently deal with mental health emergencies is untenable and unsustainable for the loved ones who care for those with severe mental illness.

After my husband's first hospitalization he was misdiagnosed with major depression, started on a medication that then triggered hypomania that was not recognized by his outpatient psychiatrist who failed to have his inpatient records due to lack of coordinated care. He was still suicidal, but had become increasingly irritable and paranoid. It became nearly impossible for me to convince him to see a healthcare provider again; he threatened to run away if I called 911.

When I did finally get him an appointment it was with an internist who didn't know him. Due to his paranoia, though he was never threatening, she called security and he ran away while we were walking him to the Urgent Care for admission. The police were called, but were mistakenly told that he had assaulted someone, which he had not. He had simply dropped his backpack at my feet and took off. He eventually contacted me hours later and I reasoned with him to get him to return to Urgent Care. The social worker that night was not well-versed in psychiatric admissions and, after waiting for many hours, he again fled Urgent Care, despite there being a security guard stationed outside his sparse exam room. The police found him and he was taken to another ER and held in four-point restraints, though completely compliant, for nearly 20 hours waiting for a psychiatric bed to open. I was called by the Mental Health Professional (MHP) the following morning to discuss his involuntary hospitalization and the process for testifying as a family member, essentially against him, to ensure he could be held. Had my husband had ongoing assisted outpatient treatment, a shorter wait in the emergency department, or the ability to interact with emergency responders with knowledge about SMI, it may have prevented a misdiagnosis and much pain for us both.

We can do better in healthcare; we can do better as a society. Covid-19 has unearthed the scourge of mental illness in our communities. Thank you for taking substantive steps to address this issue.

Response 2:

Dear Chairman Wyden,

As a clinical social worker and sister/legal guardian to a brother with schizophrenia, I am appealing to you for more resources (supportive housing; medication management resources as many psychiatrists are unwilling to treat people with schizophrenia; support for family members; and making it easier to hospitalize someone who has decompensated and is psychotic). Most families feel overwhelmed caring for a family member with severe mental illness as there is very little financial, emotional, or logistical support.

There is often the appearance of resources which in reality do not exist. For example, I have contacted Transitional Resources in Seattle, Washington five times to talk to the housing manager about supportive housing for my brother. I left messages asking about how to apply for housing. The housing manager returned one of my calls but never responded to my question.

Prior to relocating my brother to Washington so I could provide support and act as his legal guardian, he resided with my mother in New Mexico. When she became gravely ill and later died, my brother decompensated, lost 80 pounds, and was psychotic. Neighbors would call to notify me that he was psychotic and that the police had come to question him at my mother's townhouse. He was never taken to a hospital to be evaluated and the police would never respond to my calls. When I attempted to meet with my brother's psychiatrist to express my concern about his mental health, the psychiatrist was initially unwilling to meet with me and was unwilling to issue a pick up order with the police so my brother could be evaluated. When I called the director of the clinic, they assigned a case worker to go to the house to meet with my brother. Because my brother would not let the case worker into the house, the clinic dropped my brother because he wasn't "interested in treatment". I worked with a guardianship attorney and different psychiatrist to get my brother hospitalized and stabilized.
This experience was deeply traumatizing to me as I sought to locate resources and help for my brother. I have been a mental health provider for almost 30 years. I cannot imagine what the experience is like for others in the same situation without my background in mental health. Many of the clients that I have worked with through the years have had a family member with a severe mental illness. They too have struggled to find resources and support.

Please consider these thoughts and suggestions.

Response 3:

Dear Chairman Wyden,

I am writing this as my son, with SMI, is suffering, and trapped in a broken system. He is living proof of the existing barriers to treatment for individuals with serious mental illness (SMI) that are in the criminal justice system. He has been in San Luis Obispo County jail, San Luis Obispo, CA for the past 18 months. His status is "Incompetent to Stand Trial" and he is waiting for a bed at Atascadero State Hospital, Atascadero, CA (The current wait list is approximately 1,800). He has been in the Jail Based Competency Program twice, but never truly restored to competency. Every day he remains untreated, his mental and physical decompensation worsens. The criminal justice system is not equipped to handle individuals with SMI, and the long wait for beds is detrimental to the inmate, families, and the community. No one should have to endure the wait for treatment AND proper care. I am pleading with you to take action. Repeal the Medicaid Institution for Mental Disease (IMD) exclusion, fund programs that are tailored to community resources, and divert people with SMI away from criminal justice involvement to the greatest extent possible.

Response 4:

Dear Chairman Wyden,

This letter is regarding barriers to treatment for individuals with serious mental illness (SMI) in the criminal justice system. My nephew with SMI has been in an incompetent status in San Luis Obispo County jail for the past 18 months waiting for a bed at Atascadero State Hospital. Every day he remains untreated his mental and physical decompensation worsens. The criminal justice system is not equipped to handle individuals with SMI. Subsequently my nephew should not have to endure the wait for treatment. I earnestly urge you to repeal the Medicaid Institution for Mental Disease (IMD) exclusion.

Response 5:

Dear Chairman Wyden,

This letter is regarding barriers to treatment for individuals in the criminal justice system with serious mental illness (SMI). My nephew who suffers from SMI has been in an incompetent status (unable to go to trial) in the San Luis Obispo County jail, San Luis Obispo, CA for the past 18 months. He has been waiting for a bed at Atascadero State Hospital. Every day he remains untreated his mental and physical decompensation worsens. The criminal justice system is not equipped to handle individuals with SMI. Subsequently, my nephew (and others) should not have to endure the wait for treatment. I earnestly urge you to repeal the Medicaid Institution for Mental Disease (IMD) exclusion.

Response 6:

Dear Chairman Wyden,

One of my dearest friend's son, with SMI, is suffering, and trapped in a broken system. He is living proof of the existing barriers to treatment for individuals with serious mental illness (SMI) that are in the criminal justice system. He has been in San Luis Obispo County jail, San Luis Obispo, CA for the past 18 months. His status is "Incompetent to Stand Trial" and he is waiting for a bed at Atascadero State Hospital, Atascadero, CA (The current wait list is approximately 1,800). He has been in the Jail Based Competency Program twice, but never truly restored to competency. Every day he remains untreated, his mental and physical decompensation worsens. The criminal justice system is not equipped to handle individuals with SMI, and the long wait for beds is detrimental to the inmate, families, and the community. No one should have to endure the wait for treatment AND proper care. I am pleading with you to take action. Repeal the Medicaid Institution for Mental Disease (IMD) exclusion, fund programs that are tailored to community resources, and divert people with SMI away from criminal justice involvement to the greatest extent possible

Response 7:

Dear Senators Wyden and Crapo:

Thank you for your request for federal policy solutions to behavioral health challenges and shortages. I have suggestions in two areas:

Perinatal mental health:

(1) Allow mental health professionals to bill under a "pregnancy" diagnosis code, so that they can deliver perinatal mental health preventive interventions. There are effective interventions that can be delivered during pregnancy to prevent postpartum depression. However, mental health providers have to provide a mental health diagnosis code to bill, which defeats the purpose of prevention (i.e., the woman does not yet have a mental health diagnosis, we are trying to prevent that). See: https://www.nytimes.com/2019/02/12/health/perinatal-depression-maternal-counseling.html

(2) Provide for licensing/funding avenues for community health workers (and if possible, nurses, doulas, health educators) to deliver mental health educational interventions and be reimbursed.

(3) Require state Medicaid programs to reimburse CPT codes that can be used for postpartum depression prevention by a broad range of health workers. Given the USPSTF recommendation, these services should be covered under the Affordable Care Act, but the procedure codes are currently only reimbursed in California. Useful CPT codes for postpartum depression prevention include: 98960, 98961, 98962, 99407-99407, or other patient education codes.

Behavioral health for justice-involved individuals:

- "Justice-involved" covers a wide range of individuals: from those who call 911, to police contacts, to arrest and pretrial jail detention, to court, to probation/parole, local jail sentences, and state/federal prison sentences. The biggest challenge is that about 10 million people are arrested per year and held in pretrial jail detention, typically for only a few days (up to a few weeks or months). More than half have mental health problems and as many as ¾ have substance use problems. They are back in the community quickly. Because of the rapid turnover between community and jail and back again, it is difficult to connect individuals who pass through jail to needed community services. This is made more difficult by the fact that many of the needed services are linkages between jail and community. However, Medicaid and standard community mental health dollars cannot be used for these linkage services or for mental health services that begin in jail and continue in the community. Jail staff are not supposed to contact individuals after release, and community mental health cannot be reimbursed for in-jail or linking services. Therefore, life-saving linkages to community treatment do not happen, and individuals with mental illness continue to come in and out of the jail. My suggestions would be:

  - Allow Medicaid dollars and standard (rather than general fund) community mental health center dollars to be able to be used for transitional mental health interventions (i.e., those that begin in jail and transition to the community when someone is released) or for jail-community linkage services.
  - Adequate fund community mental health centers so that fewer people fall through the cracks and wind up in jail due to mental illness.
  - Reach out to https://stepuptogether.org/, an initiative led by the Council of State Governments, the National Association of Counties, and the American Psychiatric Association Foundation to keep individuals with mental illness out of jails, and ask what else you might do to help with this issue.
  - The US incarcerates many more people than any other country in the world, many of whom have mental health and/or substance use conditions. Work with states and counties to provide stronger community mental health treatment services and to enact diversion and other programs to effectively treat individuals in the community and keep them out of local jails.

Response 8:

To: Finance Committee, United States Senate

A large population of patients with behavioral health needs has largely been overlooked by both medical professionals and Behavioral/Mental Health clinicians. These are people who suffer chronic pain and other physical symptoms caused not by organ disease or structural abnormalities but by psychosocial stress. More specifically, they suffer from so-called medically unexplained symptoms, chronic functional syndromes (such as fibromyalgia, irritable bowel and many others) and chronic non-structural pain. Collectively these conditions are called psychophysiologic disorders and they comprise 35-40% of outpatients in primary care (1).

Unfortunately, few healthcare professionals have had any formal training in how to diagnose or treat them. The result is a blind spot in the healthcare system that leads to years and even decades of unnecessary suffering, frustration and cost. This appalling situation does not need to continue. Recent controlled trials (2-6 below) show the dramatic benefits of innovations in psychotherapy for these conditions, one of which was also recently endorsed by the Dept of Health and Human Services (7, page 38).

Three changes that federal legislation could support will enable this effective, evidence-based care to reach those in need. First, the Primary Care Behavioral Health (8) model of care should be more widely adopted because these patients require collaboration between medical and mental health professionals to achieve the best outcomes. Second, healthcare professionals need education about the new approaches to psychophysiologic disorders to overturn the now obsolete paradigm that these patients are not amenable to accurate diagnosis or effective treatment of the underlying causes. Third, a diagnostic code for Psychophysiologic Disorders would help focus attention on and facilitate billing for this diverse group of conditions.

I would be glad to speak with Members or staff of the Finance Committee at your convenience.

Response 9:

Dear Chairman Wyden,

Please read my update to my first message sent to you on 10/31. Our son was discharged and to our dismay after one week his providers could not or would not do any more for him and thus discharged him, still hallucinating and delusional. While he is minimally participating in an outpatient program, I can't even describe the feelings of disappointment, and shock, of now our having to be fully responsible for his care and wellbeing. He went from being in a locked and staffed unit with multiple drs, nurses, social workers, students, mental health contacts, housekeeping, security, and meal provisions for 425 days to his two parents with no help whatsoever.

24-hour care will be needed, exclusively our responsibility. We will do all the cooking, cleaning, driving him to appointments, and medication dispensing. We can't leave him alone so we will take turns to do errands. We will have to find and pay for private help to give us a break occasionally. We worry about his untreated symptoms and medication side effects and must deal with those issues in our home which can be very stressful. We are worried about each other and our own stress and health, and our family business. We can't imagine what will happen if one of us becomes ill or dies and can't help the other. The stress and worry are unimaginable and feel our lives are effectively over already.

There is a gaping hole from when a person is inpatient to being discharged - to the family, who doesn't have all that incredible care available, and this applies to those especially with UTRS and TRS. We need help. Let's be clear, many are simply discharged in to an uber or the street. At least fund and help this specific group of people with treatment resistance and their caregivers, if you can't solve the homelessness crisis. I don't know what the answer is, but it is unconscionable that we still as a country ignore these people and families who are in crisis…and during a pandemic no less. My GOD, please just imagine this happening to one of your children. What would you do? You would then find out how terribly broken our Mental Health System really is. It is a devastating sudden nightmare that no one is ever prepared for.

Our son is the sweetest, kindest, smart, and beautiful person. You would have enjoyed a conversation with him prior to his sudden illness. He is not violent or a danger to the community. He was a Democrat who believed in equality for all. He didn't do drugs or smoked. He loved acting and the theater. He adored Lady Gaga and loved his family and friends. He does not deserve any of this.

If you believe in human dignity, equality and decency, please show compassion, and change the future for so many suffering with this unbearable disease by doing the following:

- Repeal the Medicaid Institution for Mental Disease (IMD) exclusion

- Repeal the Medicare-190 day lifetime limit
- Expand federal funding for assisted outpatient treatment (AOT)
- Establish a national database of psychiatric beds in the U.S.
- Request a Government Accountability Office (GAO) report on the extent of psychiatric boarding in emergency departments in the U.S.
- Require the National Institutes of Mental Health (NIMH) to establish transparent and peer-reviewed standards for estimating prevalence rates for schizophrenia in the U.S.
- Mandate periodic NIMH prevalence studies of schizophrenia, bipolar disorder, and other severe mental illnesses at regular intervals, and explicitly require that prevalence rates be accurate and comport with peer-review protocols
- Fund programs that are tailored to community resources and divert people with SMI away from criminal justice involvement to the greatest extent possible
- Include emergency responders with knowledge and experience with SMI— including but not limited to schizophrenia, bipolar disorder, major depression, and other psychotic disorders— in both the planning and implementation of any emergency response models
- Enforce the bipartisan language in the 21st Century Cures Act that requires the Department of Justice and others to collect and regularly report data involving law enforcement encounters and mental illness
- Include racial and cultural demographic information in any data collected to inform future funding and policy decisions related to the treatment of mental illness, as well as reform efforts to prevent and reverse criminalization of SMI
- Make permanent all telehealth coverage for Medicare recipients that were expanded under Section 1135 authority during the COVID-19 public health emergency

Response 10:

I am writing in response to letter dated September 21,2021 asking for solutions/ideas to enhance behavior health care. My son, struggled with anxiety , depression and substance use and sadly passed away on December 29, 2020 of a substance use overdose. In the two years before his death he had trouble accessing mental health care, especially as he moved from Colorado to Pennsylvania back to Colorado and back to Pennsylvania. During covid his struggles were worse. He felt more isolated living by himself in Colorado, lost his job due to covid, and had a car accident where he was prescribed opioids in the ER. Each time he moved he needed to access a new healthcare plan and new doctors. In Pennsylvania we could not find him an in network provider for mental health care.

We need an improved healthcare system that includes mental health care.

We need insurance companies to include all care providers, and pay those providers for their services. Many mental health providers do not accept insurance because the insurance companies only pay half of their fee.

We need a health care system that will work across state lines.

We need to reduce the stigma of mental health, especially for young people.

We need easier access to mental health and crisis care.

There are no easy answers but I am willing to work together to make improvements. I would welcome the opportunity to share my story in greater depth and work towards solutions. We have to do better. Too many young people are dying. Sadly I learned yesterday of my friends 23 year old daughter taking her own life due to mental health disorders.

We have already reached out to Senator Casey with a letter. I look forward to your reply.

Response 11:

Dear Chairman Wyden,
My son was diagnosed with schizophrenia at the age of 15, he is now 44, It was always difficult to get treatment for him. When he was in crisis and needed in patient care, it was hard to find a bed for him and when I did they would only keep him 5 days or less. He was in and out of hospitals because they would only stabilize him then release him. My insurance had a life time limit and after that no treatment is available.

Response 12:

Senators,

Thank you for your interest! I am a Licensed Professional Counselor and have been working in a federally funded community clinic in Lane County (Brookside Community Clinic) for four and a half years. I worked at Emergence before that, and was in private practice before that, in Bend.

I worked in the clinic until Covid, then I started working remotely which is what I do now. 99% of my patients are OHP (Medicaid) and Medicare also.

I do therapy mostly by phone. I'm good with technology and most of our staff meetings are by GoToMeeting or Microsoft Teams platforms. I've done virtual visits (video calls) several times but it never works out well for one reason or another. Most patients aren't comfortable with technology or they don't have wifi or even a smart phone. My patients are all referred to me by the doctors and other PCPs. I talk with them for an hour once a week. In theory Integrated Behavioral Health should be dealing with mostly health related concerns like diabetes management and other physical health related issues. In reality most of my clients have depression, anxiety, family problems. PacificSource is forcing us now to go back to their strict IBH model of 30 minute appointments, no therapy, just skills for stress management, solution focused therapy, brief solutions. Or they won't pay us. That is a problem. We are supposed to only see patients for 5 or 6 sessions (phone calls) and then pass them off to a counselor in the community. Only there aren't enough of those. And all--ALL--the MH prescribers are booked way way out, not taking new patients. So Pacific Source is running the show and they tell us what to do and the patients will lose out.

I'm tired. I don't have the answers you're looking for but I appreciate you asking the questions. I stay at this job because they pay me well and because sometimes I feel like I help. But it is exhausting. I look around sometimes for a job driving a truck, or anything other than talking on the phone.

Here's what would help my patients/clients:

Forgive student loans.

Make community college free.

Teach emotion regulation, mindfulness, and relationship (couples counseling) in schools.

Free childcare would ease the stress of my patients who have young children.

Use behaviorism techniques for the homeless situation. I know that is unpopular, everyone wants to give free housing to the people addicted to meth, heroin, alcohol, and they think with housing they will be better able to give up their addictions. Not so. That is not harm reduction. Reward good behaviors, punish unwanted ones. On the other hand some of the homeless do not have addiction problems and they just need money and more housing. Without ruining the green spaces in Eugene.

I am just rambling now. We need more mental health providers. Train them in community college. It is not rocket science: Be kind, be authentic, listen and use mirroring, teach behaviorism and DBT concepts as well as basic psychodynamic theory. Teach MI. Teach them boundaries and confidentiality. Then set them loose to help others. Addiction counselors need more training than they get. Again, behaviorism techniques, not AA.

Response 13:

Hello - I am writing in regards to my friend from WA (constituent of Sen. Maria Cantwell) who is gravely ill. He has been tortured for several years without light at the end of the tunnel. He has been subject to many studies, testing, and trial medications but every specialist, doctor, etc. has not been able to figure out what is going on. We have been told that he is the sickest patient any of these experts have treated. It's heartbreaking. From a top performing student at a highly competitive private institution, this regression has put such a strain on him, his family, and his friends. The most recent hospital stay was over 400 days long and counting. We miss him so much. I miss his laugh, our fun moments, our trips to our favorite diner. I worry that he will never be the same again. Please consider implementing the recommendations provided by the Treatment Advocacy Center. The treatments and resources that my dear friend has received are inadequate. Additional studies, funding, and resources to reduce the systemic barriers between people with severe mental illness (SMI) and treatment are critical. During these trying times, bipartisan support and action to ensure resources for the gravely ill is essential. Thank you for your time and consideration.

Response 14:

Dear Chairman Wyden,
Mental Health as a system was attacked by Ronald Regan back in the days and has not ever recovered. We need emergency psych. services mobile units, EPS style hospitals in each and every state. Santa Clara County has some pretty good models to check out. My cousin in Washington state became seriously mentally ill and the poor, underfunded services in that state

has caused my family agony and hell for 3+ years. Anybody can slip through the cracks of the WA State system. My cousin would be dead if not for the constant pursuing by his parents. That system is inadequate, the families and the client suffer. I have been a provider since 1984 and I have seen good MH models and poor ones. There must be wraparound services and early detection and prevention in order to tackle even a few aspects that need to happen in order to get a person to function in a lesser level of care than a hospital. Sub-Acute facilities should be everywhere. Mental Health Drug Treatment Courts are affective and should be in as many counties as possible. Look up Judge Steven Manley Santa Clara County. There should be some real research on the models that work the best and included in MH programs across the state. I am available for further comments.

Response 15:

Dear Chairman Wyden,
please do all that you can to improve mental health like the proposed senate items and remove some of the hippa barriers for family members of those with mental illness .

Response 16:

Dear Chairman Wyden,
Our son was diagnosed with Schizoaffective disorder at age 28; he lives with us (72 y.o. parents) now. We have a shortage of hospital crisis beds for treatment in Seattle. Repeal the IMD exclusion & increase psychiatric beds. Our state Legislature is paying for redesigning Crisis Response system that is broken & failing our ill citizens....we need trained people in emergency response and much more Assisted OutpatientTreatment (wrap-around services) to help people recover when leaving the hospital, as well as housing to recover in! Please fund proven strategies to directly help the most Seriously Mentally Ill and their aging caregivers (that isNOT Mental Health First Aid). Thank you Senator Maria Cantwell, my Senator.

Response 17:

Dear Chairman Wyden,
Please senator, we need your help. My son with severe mental illness (schizophrenia) was tased by police during a mental health crisis he was experiencing because there were no responders with knowledge and experience dealing with severe mental illness. He then had to wait at emergency room for over a week due to no beds being available at mental health hospital. Also we need community programs/resources that help SMI to stay away from criminal involvement. Thank you.

Response 18:

Dear Chairman Wyden,

My son and daughter suffer from mental illness, my son has schizoaffective disorder and OCD, and my daughter has schizophrenia. It took at least 10 years to get my son into treatment due to the famous “criteria “ which demanded to have my son homeless and starving. I have the opportunity to be in contact with many police officers who were very concerned about what the law was according to them “if your son is over 18 and wants to be homeless is his right” they didn’t had any experience or training about mental illness, if 10 years ago there were emergency responders with knowledge and experience maybe my son could have recovered quickly and had a different outcome in his life then his current “existence I have now my daughter who is refusing to work with her psychiatrist and resists changes in medication and help. She has been many times to the hospital with 5150’s and the hospital releases her in three days due to lack in beds and what do we get? An upset mentally I’ll daughter who can run away and put herself in danger. The help for mothers and children like mine is basically nonexistent.

Response 19:

Dear Chairman Wyden,

Thank you for considering a federal change in how we treat mental health. I am the mom of a teen with severe depression and suicidal ideation. Even with private health insurance, my treatment options are limited. Only in a crisis situation, can one find a pediatric bed our outpatient program available to them. We’ve already been on the waitlist at multiple places for intensive outpatient therapy and are in the fourth month of waiting. My son would need to have a serious suicidal attempt in order to receive an in patient bed. In the meantime, we are left struggling on our own with a therapist to get him to go to school, leave the house, see friends and protect his life. Please consider:
Expanding federal funding for assisted outpatient treatment (AOT) And Establishing a national database of psychiatric beds in the U.S.
These additional resources for pediatrics, not just adults will have a profound impact on parents that are dealing with kids and teens struggling with mental health.
Thank you for your consideration and advocating for teens with mental health diagnosis.

Response 20:

Dear Chairman Wyden,

I am a retired medical social worker, aunt of a young man with schizophrenia and I live in Seattle, a city with an enormous homeless problem. I believe much of the issues we have today with barriers to mental health care date back to very bad legislation in the 1980's which closed treatment facilities without providing alternative care. I believe the way out of our present crises in Emergency care, homelessness and overwhelmed justice system starts with accurate data around numbers of patients with serious mental health disorders, number of them in inappropriate care (ED hallways) and funding outpatient treatment programs.

Response 21:

Dear Chairman Wyden,

The only available places open for a person who suffers from Serious Mental Illness is jail or prison. No one will communicate with us the family supposedly cause of hippa laws. There are no care homes designed specifically for people who suffer from SMI. If the mental health industry is the one that has turned its back on caring for these people do youguys honestly think people working in law enforcement will? Each time my loved one has been sent to prison the condition has become much more severe, and now Youguys expect them to find a willingness among themselves to change? Also considering that once released from incarceration they are expected to fend for themselves, considering that the medication received might have added to their condition becoming more severe? Im asking to allow family to participate in the care of our adult loved one. Please I beg you give us tools to work with. Please reconsider a different approach to working with Severely Mentally Ill people.

Response 22:

Dear Chairman Wyden,

Most care homes are not equipped to handle Seriously Mentally Ill people, more so if the person has a history of incarceration. Most care homes will not accept them. A solution is to cut what is wasteful so the resources can go to what is useful. Cut peer support programs, stigma programs, suicide advertising, and programs that claim to predict or prevent mental illness. Cut all mental health programs listed in SAMHSA's NREPP database that don't improve meaningful outcomes for people with serious mental illness.A balkanization of mental health funding prevents funding from helping those who need it most. Medicaid does not support hospitalization for people between the ages of 22 and 64. A smart approach is to combine all the multiple funding streams into one single department, within a single low level of government that would be responsible for all things mental illness in the locality. The department would be responsible for everything: housing, treatment, education, job training, CASE MANAGEMENT, INPATIENT TREATMENT, OUTPATIENT TREATMENT. It should even be billed for- the cost of arresting, trying, and incarcerating those with mental illness in order to create an incentive to reduce those costs. Ive looked elsewhere for different solutions cause the current approach leaves out people who suffer from SMI and directs the majority of the funding to people categorized in the "worry-well" population.

Response 23:

Dear Chairman Wyden,

Our "gifted" son headed off to Pitt 2015 and in 2016 was hospitalized (1st of 4) with what would later be diagnosed as schizophrenia. 4 different in patient stays at different facilities in 3 yrs and if he didn't have us showing up w "history" or family input, he would not be stable. Medicare benefits kept us safe from his delusions and kept him safe while changing meds. Please don't take away the benefits that have helped him and continue to help w necessary therapy.

Response 24:

Dear Chairman Wyden,

I am the proud mother of a son diagnosed with child onset Schizoaffetive Disorder. My son was only 11 years old when he had his first "mental break ". He was hallucinating that a green monster with many arms was there to hurt him. He wanted my mother to get her gun to shoot it. Up until this point we had sought help because we knew there was something different about my son. For years we were told he was " strong willed or spirited ". We weren't taken seriously and we're basically told it was our parenting that needed improvement. For awhile I believed that because I was only 19 years old when I had my son. I have fought long and hard and have grown weary trying to protect and advocate for my son and family. He is 21 now and stable, but getting him to this point was years of hard work and cost us dearly financially, mentally, and emotionally. You see when he was just twelve years old he was inpatient at a mental hospital in Tulsa called Shadow Mountain. It was here that my son was "raped by instrumentation ".by an employee there just days after coming out of the suicide area. I didn't learn of this rape until four years later when he was 16 and shared what happened to him. See in 2013 he had to have surgery on his penis due to a dorsal web or something like that, that was mostly caused by what happyto him. He still suffers with PTSD and has constant nightmares about it. That hospital is now shut down and we're in the middle of a civil suit with that company. However I am glad that place is no longer in business, I'm also heartbroken that there are that many fewer beds available in our state. We desperately need more resources, both inpatient and out for a whole community of people who suffer from this debilitating and unasked for illness. My son, spent his 18th Birthday at a courthouse voluntarily signing over legal guardianship to his dad and I because unlike a lot of other with the same illness. He has the self insight to know that if he is ever unstable again, he wouldn't want us locked out of making decisions for and helping him get back to his baseline. I beg you to please show up and do the right thing for our SMI community, who did not choose to be ill, especially an illness such as this.

Response 25:

To Whom it may concern,

I live in Napa, California. I am writing to you because I feel compelled to see if I can help make some much needed changes to our housing assistance and for mental illness treatment which often go hand in hand.

The situation is so overwhelming it is hard to know where to start for most people, even our leaders. I can not keep this to under 800 words, but I hope you will read this anyhow. It is long, but needs to be told.

My husband and I, have had the unfortunate luck of having an adult son who has experienced both having unclear mental condition(s) (Bipolar / Narcissistic Personality Disorder / ADHD / Anxiety, possible CTE from football) and being homeless several times. I have some ideas on how to improve upon "the system" having lived through this mess, we have seen how disfunctional the system is. There is nothing worse than seeing your child suffer these kinds of issues, when the help can't help him.

A little back ground on our situation…
While younger, our son started life with a forgetful memory and very stubborn streak. We would think, it's just how he is, after all ADHD meant someone who was very figity and very active, this was not our little day dreamer. Although, always a stubborn child, we were not aware of just how severe some of his tendencies would become in early adulthood. He was like me in school, quiet, day dreamer, had to put in a little extra effort to concentrate in a classroom setting. He was a little aloof and disconnected and I would say actually very hermit-like with only a few really good friends. He would argue a lot but being young, I just saw this as stubborn and forgetful. Ask him to do 3 things and I would be lucky if he did one of them to satisfaction. At the suggestion of his 4th grade teacher, we had him officially tested for ADHD, and surprise he was. Little did we know, this was just the tip of the iceberg.

We signed him up for a boys only group put on by a therapist at Kaiser in Vallejo, CA. I would say it was helpful, but we didn't see a huge change in his behavior.

We tried meds on him, we thought at the time that his ADHD could be contained, if he just focused harder, without the medication. We would talk to him about it and he would decide he didn't like taking the meds and trying to focus really hard would be his path. I remember telling him if he didn't want to take the meds, he would have to buckle down and try SUPER hard to focus on his teachers and homework. After all, he never had trouble focusing on video games for hours at a time. We started every year on meds and within a few weeks, he would be physically throwing up (I think he would almost have anxiety attacks on the meds) and then he'd decide to stop taking them.

When I would talk to Alex it seemed like "normal" boy behavior stuff that he was dealing with and he was never an obnoxious child, in fact he was actually a very sensitive boy who could be very kind and thoughtful, on occasion.

We could not figure out why the meds made him feel so horrible. If it was not for football, he might not have made it out of high school at all, let alone with a C+/B- GPA. The High school had great coaches which held their players to the higher standard, that helped to motivate him to do good in class. How ever he had to get there, he did. We hired tutors, he had an IEP all through school (since 4th grade) although he tried hard not to use it, occasionally it became necessary. Thinking ADHD was his only issue, we did not push any other medications or push getting him to a psychiatrist/psychologist.

He graduated in 2012 with many friends and a decent GPA, football was good for him. We set him up in a house with other football players at Santa Rosa JC so he could focus on his school and football and that was it. We did not require that he get a job too as we thought it would be too distracting for him to do all 3. It was becoming more and more evident that he was not good with time management. We went to see him often and to look in on the house, to see if he needed anything.

Football season, that year, went great. We went to every game we could to support him. He was an excellent lineman and long snapper. He played left guard and could fire the ball like a rocket from a center stance when long snapping, he had talent. At 6'3", 250#'s, he was built for football, hard to move and very strong. Staying healthy and working out were now a huge part of his life, promoted by the football program. It was during this time, he learned how to eat healthier (during childhood, it was very hard to get him to eat anything resembling a healthy menu) and how to properly workout for building strength and stability. He was doing it all on his own. I was so proud of him.

By late fall of 2012, his first year on his own at the JC, he called me a couple times in tears feeling under pressure and really depressed. He argued and demanded a lot from us. He'd register for classes at the wrong location. He wouldn't show up to classes or show up at the wrong day or time. The first year of college is always hard for kids. Being away from home, on your own, some students don't adapt well, Alex was turning out to be one of those. We thought that it would pass and that this was just an adjustment period for him, part of "growing up". We supported him as best we could, but I suggested he go talk to someone at Kaiser which was not far from his home in Santa Rosa. He did, after a couple of missed appointments. Some new patterns started to emerge. A pattern of him blaming us for everything wrong in his life and everything else under the sun. It became a steady stream of rage and accusations. His demands seemed to increase along with some pretty severe mood swings. I suggested he go ask Kaiser to get back on ADHD meds as that might help his focus and thereby lower his stress levels.

He made it through his first semester. By this time, he was about 18.5, almost 19, he was now an official adult. It was difficult to get information from him about how classes were going or what he had been working on or even how he was feeling and doing with school. We could not call the school and ask anything. We would get a "we can't disclose that". I would ask him about his appointments, all I'd get was "it was fine" with little to no follow up information.

All seemed somewhat ok, until the spring of 2013 when he decided to change positions on the football team. He dropped 50#'s very quickly and changed to full back a position that required a lot more running. Mind you, he was not a kid that was fleet of foot, he was a perfect lineman with tree trunk thick legs, but he wanted to play a more "glorious" position, I guess.

Spring training went ok, summer was uneventful. We notice he was arguing a lot more, and sometimes screaming at us for things that were not our fault, fighting us over EVERY little thing he felt was our fault. We were willing to help, but in my world, you don't ever talk to your parents "that way", ever!

In the fall of 2013, we got a call in the late afternoon, Alex had been sent to the hospital for a knee injury. It didn't seem to be torn or anything that might cause permanent damage, so they sent him home with instructions for care.

A few weeks later, another call. This time he had been sent to the hospital by ambulance after being knocked unconscious by another teammate in practice. They did a scan (either MRI or CT, can't remember) and determined he might have a concussion, but nothing showed up on the scans. We (his sister and I) stayed the night with him at his house to make sure he was OK.

He followed his home instructions from the Dr., to the "T". No TV, keep things dark, no bright lights, so he hid in his dark room, maybe he read a bit. After a few weeks of being "out on injury", he eventually decided he didn't want to play football anymore. I thought that was a good decision and we decided he should move back to Napa, with us, and go to our local JC that is 3 blocks away, since he would no longer be playing football.

In the fall of 2013, everything changed the night he moved home. That night, I walked in from work and was very excited to see and talk to him, as I hadn't seen him in a few weeks.

He was in a really bad mood, nasty and argumentative. I left him to setting up his printer in his room. As frustrated as he was, I figured it best to leave him alone for the moment. I went into the kitchen and proceeded to steam some vegetables for my dinner.

A few minutes later he came out looked at my veggies and proceeded to get within a couple inches of my face, spitting mad, and screamed at me for eating too few veggies. I told him it was fine and eventually had to tell him to leave me alone. He would not. He proceeded to scream at me some more, only a few inches from my face. I could feel mist from his mouth on my face as he bellowed. I backed into the corner, he followed with a challenging stance. Keep in mind he's about 220#, 6'3" about a foot taller than me and in very good shape. I am 5'3". In my world, I would never have talked to my parents disrespectfully, let alone scream at them like this. I was trying to get him out of my face. He would not go, or leave me alone…all over vegetables I was cooking for myself. I slapped him hoping he would back off and get out of my face and reminded him that I was still his mother. It had quite the opposite effect. He slammed me into the cabinets as if I was one of his football colleagues. He would not stop. We got in a fist fight basically. The evening ended with the cops coming and making him leave for the night. I ended up with bruises on both my hips and forearms and in total shock from the moments before. He had never screamed at me like that, let alone physically slam me. This wasn't something kids do to their parents, in my book, ever. I didn't understand what was happening, this wasn't my Alex.

He stayed with a friend for about a week. We agreed to let him come back home if he went to family counseling with us. He did. He seemed really remorseful and tearfully regretted doing what he had done. We went 1 or 2 times and seemed to create some boundaries as far as, when I said I needed space, he agreed he would back off and give me my space. Eventually, he would not, and once again subjected us to more verbal abuse and control issues.

Back at home, all went well for a week or so. Then, one day, he started throwing out all of our "bad" food, while yelling at me for not eating better. Anything that was not organic or bad for us hit the trash can. Other than physically try to stop him, there was nothing we could do, and he knew it now. Keep in mind, this was not his food, it was food we had purchased. My husband does most of the cooking and we like a lot of variety. This was not ok with Alex and would not stop throwing my food out, perfectly good food.

This was the beginning. Over the last 8 years, we have been to therapist after therapist. He tries meds, then throws them out, then says he needs them, then throws them out again. We have been bludgeoned with verbal abuse and threats on a continuous basis. We have been called names of every kind, been told that we are the problem, not him. We have been the subject and target of his rage, had our stuff vandalized, broken, ripped up and discarded. He's threatened my dogs, my house and my belongs with fire.

Our frustration was mounting at an exponential pace, all while trying to figure out why he was acting the way that he was, the doctors couldn't talk to me about his appointments or a possible diagnosis, nor did most want to even listen to me.

Most info that I know now was because I had to find out for myself, support groups or books or friends. I often had to talk to Alex's Dr.s to be sure to put their best foot forward and knew what they were working with. I would tell them, "I know you can not tell me any information, but YOU CAN listen to me!....". In fact, I would have to demand that they listen to me as the story from Alex was much different than my version. They needed the full picture.

Alex wouldn't tell them much, and there often wasn't much they were willing to do for Alex. Therapists often do not know how to deal with Alex. He's manipulative and forceful and very derogatory. He's berated us and several therapists. He's been homeless, slept in his car, slept in shelters and eventually, we had to put a restraining order on him then subsequently have him arrested. We have called the cops several times and been told there is nothing they can do without him being the first to make the connection. When he lived with us, we never knew which Alex was going to be in the room when we got home, really sweet and kind Alex or Enraged Alex. He is no longer welcome in our home and has been homeless a few times. The last time for about a year. At this point, we have not spoken in a couple years, due to the restraining order.

Fast forward to today. In September, both of my Parents (mom and step-father) were shot and killed by my step dad's son who then, killed himself. He had suffered from a couple very similar issues as our son, which worries me quite a bit. He was also experiencing the frustration of not being able to work through COVID and struggling with vagrancy and not being able to get himself medication for his issues. The tension was mounting between he and my step dad on a daily basis, they were not getting along and arguing more, similar to what my own son and I go through. Needless to say, I have some experience and perspective on mental illness and how to possibly help them.

Some issues that I believe could be resolved, if we had some lawmakers support. These are big uses, which if we can help fix, the government might not need to be so involved. Let me get to my suggestions:

HOUSING - The first and most obvious.
 - Need more tiny home villages/land for these servives (see https://www.hhhservices.org/)

- Quicker help for money for services (Section 8 with appropriate rent limits – too small for around here) The waitlist for our son was 8 YEARS, IF they even took names at the time.
- Less restrictions (Section 8 won't let my son have a roommate or provide enough $$ to live in a solo unit)
- Wait lists too long (not many options)

Yes, there are shelters, but when my son needed them, there was a 6 mo. wait list. The night he was released from jail, he slept under a bridge with not much more than slippers and sweats. It is estimated that over 50% of most homeless people probably suffer from some kind of mental issue which may prohibit them from having a roommate type situation. It is nearly impossible for some to live with others, even family, based on my own experience with my son. It has to be single occupancy. I think my son has lived in over 10(?) roommate situations. Some only lasted less than 30 days.

I know no one wants it in their back yard, but if not in the back yard, then it will migrate to the "front yard"....they have to have a place to go when they get kicked out from under the bridge. A 6 month waiting list to get into a shelter is too long. Which tells me the demand is outpacing what anyone is doing for the issue.

In our town, Napa, CA, it is EXTREMELY expensive to live here. There are only 1 or possibly 2 upcoming projects which will not be completed for a couple years. The project I know about is only 60+/- beds. The need THIS year has already outpaced this as you see it under every overpass in our town. In addition, it is hard to get fearful citizens to approve these projects due to the thought it will destroy their property values and promote crime in whatever area it lands in.

DISABILITY SSI –

- QUICKER response from SSI/Disability- From the time of application to our hearing date, it took about 2 years before we could get him on SSI/Disability. That is a really long time for someone to be so unstable who needs food and structure to function. I understand why some homeless people steal, they have no choice.
- EASIER approval process. Shouldn’t take 2 denials. This process is only for the really determined. I think most give up due to the process.

FOOD - (CAL Fresh?)

- Food - $170.00 from Cal Fresh doesn't go far when feeding a young adult male. They eat about $300.00 - 400.00 of food / month, that's the low side.

- Food storage for healthy foods? (non existent)

They need a place to keep food so it doesn't get stolen or go bad. The only kinds of foods that don't need refrigeration are processed and preserved foods and those are actually pretty expensive compared to fresher stuff. There's no refrigerator in a tent or car.

ACCESS –to psychologists/psychiatrists

- EASIER access to and more psychologists - Not family therapists, they don't have what it takes. People who may actually care about helping with the determination and the time to establish a relationship. Homeless and/or mentally challenged people have learned not to trust people. It takes a whole lot of time and patience to re-establish some kind of trust. The homeless outreach (through the Police department) in our town has a total of 1 counselor. It took us a tremendous effort to make contact with her. She was not in the office most days and I don't recall ever talking to her through a return call. This was me, not my mentally challenged kid, and I was super frustrated! To this day, I don't think we ever were able to make contact with her. Luckily the homeless outreach police officer was much more accessible and very helpful.

MENTAL HEALTH CARE resources through the largest providers.

- Most HMO’s counselors are not properly equipped for Severe Mental illness
- TOO few that are equipped.

Out here, Kaiser is popular. They are great for most things physical. However, they are not adequately trained or staffed to handle my sons mental issues at all. It takes a special kind of counseling to REALLY get through to some people. Kaiser also does not handle interventions or family counseling, nor do they have the capacity to offer more than 1 hour every 4 weeks. We needed sooo much more than that. Leaving us unsupported in our time of need, we had to reach to others outside of Kaiser. I must've contacted 5 or 6 psychologists or psychiatrists, all of which were not accepting any new patients.

LAURA’s LAW / Right to “peace” in my home- Give the cops the right to remove someone if they have been called for the same reason at the same address, more than a couple times.

- Need for "forced" counseling
- 3 Strikes - If you have to call the cops on the same person numerous times, there should be a limit. If you have to call the cops more than 2 times for the same issue, they should be able to remove them from the premises (Regardless of Landlord/Tenant relationship) and issue some sort of mandate for help, BEFORE it gets to arrest and jail, regardless of tenant standing or relationship.
- Attorney’s are often unaware of all resources for SMI

Since our son was now an adult, it was VERY difficult to get him help. Years of fighting with him to get to counseling, violent threats and constant verbal attacks, finally led us to put a "peaceful contact" restraining order in place as a last resort. I had to have him arrested when he became beligerant. The cops came to our house on several occasions before this, over about 4 years or so, they couldn't do a gosh darned thing, because he would straighten up when they arrived. They couldn't even get him out of the house when he was physically throwing everything in our kitchen out into the middle of the street, in the middle of an outburst.

Every time I tried to advocate on his behalf, due to HIPPA laws, I was shot down while they recited the phrase, “We’re sorry, we can’t tell you that...” “Or “what do you want me to do about it?” This was not help, it was hell. Since I was failing in the mental health department, we were told by many Therapists and Dr.’s that getting Alex into the judicial system would encourage him to stick with something for fear of going back to jail.

After hearing the same information several times, we reluctantly decided to pursue legal help, wherever we could get it. The hope for pursuing the restraining order was that the judge would be able to order him into a program that would teach him better management techniques for his mood swings, etc. and how to control some behaviors, along with, hopefully medication support.

When he had another rage cycle and started throwing things in my house, we had to call the cops again. This time, they arrested him.

We quickly found there was no help in jail. There was no psych evaluation even when I mentioned that he needed one. I asked for a psych eval the first night he went to jail. The police office told me they don't do that. Then they put him in general population....not a great choice for a mentally challenged person. He was later moved to isolation because of the way he acted toward the other inmates and he was getting death threats from them.

Only after the initial court appearance did they order a psych evaluation. When they released him, we had hoped for a court ordered structured living environment with counseling and rules where if he didn't follow them, he would go back to jail. No. They basically waggled their finger at him with a lecture and released him. We had hoped for so much more.

He was released after 3 mos. In county jail for time served. Without being able to go home as this was now off limits to him. He had only slippers on his feet, no shelter was set up for transistional housing, no money, not even a blanket to keep warm for the night. You can imagine how crushed I was that my last resort was no safety net at all. SSI was taking too long to get help (almost exactly 2 years), housing is really expensive or non existent and expects mentally ill people to abide with strict guidelines (TBRO and section 8 have criminal offense restrictions. Well, we quickly discovered that many county programs do not coordinate with each other, filling out paperwork is a huge chore for those that are challenged and for each and every service, had to repeat the info EVERY time to whatever organization could possibly help. No help was there. I believe if he had been able to collect SSI sooner, half of his issues with me wouldn’t have existed. Due to the legal process, he is now a criminal. A criminal, has a harder time finding work and qualifying for the programs that would most definitely help him and therefore being able to pay for rent himself. Those things were already tough for Alex, now, that has been made even harder, as a criminal.

As hard as it must have been for Alex, believe me not as hard as a mother who had to watch in slow motion as her son sinks to another level and then sink yet again.

As disappointed, hurt and saddened by this as I was, we held out hope that he would get it. If I had known then, what I know now, I am not sure that I would pursue legal action again. He is now a criminal. It is hard enough to get and keep work for him. Now, with a criminal record his options for a job are now slim to none.

ONE SPOT - A SINGLE solitary database (with HIPPA level security BUT an emergency approved contact for decisions and information)

- A single website / 1 SINGLE FORM WITH ALL INFORMATION to present to each organization. There are a lot of resources out there, but no one organization pulls it all together so to speak.

- Designated emergency contact – there should be a certificate or notarized form that a person can show to anyone that provides treatment for the patient that proves that they CAN discuss the patients health with anyone they need to. Requiring only a one time signature release from patient, every year or 3 years. (they could revoke at any time)

- a personal database for storage for documents instead of a file folder in the back of a car that will get destroyed or broken into. Less chance for identity theft.

The mountain of paperwork is crazy. While I will say there is some help out there, the process for filling out paperwork is daunting for a semi-normal (I say that loosely) person to fill out and super frustrating. I can not imagine someone with a mental issue having the patience to fill out and keep all records necessary for any federal or state program. Every program has more of pretty much the same paperwork to fill out and then re fill out for different agencies, which could be given to each organization. The paperwork they requested for those is ludicrous! And the expectation that any mentally challenged adult retains, organizes and remembers all paperwork necessary in the backseat of their car (along with 100% of his other belongings) is ridiculous! We can't expect rational behaviors (filing out paperwork) from irrational / unstable people, they throw their paystubs in the back of the car crumpled up in a ball.

Just how can we expect someone who doesn’t have a place for paperwork to store and remember all they need to for the next program?

The way I envision it, is sort of like a lending tree website. Fill out one full and complete application (sort of) with all pertinent information and it can be sent to SSI in their format, sent to CAL Fresh in their format, sent to TBRA or Section8 in whatever format they need, all with the touch of one button or maybe a couple of buttons.

All mental health and homeless organizations need a single contact point for all reference info. To expect a mentally challenged person to care about let alone keep track of the information is crazy. I understand why there are so many struggles when you are homeless. The paperwork is too daunting and frustrating for them.

Through the process we experienced with my son, we have found that the homeless situation is horrible around here, compounded by very expensive real estate.

There is definitely an opportunity for improvement here requiring law changes (HIPPA laws need adjusting for caregivers. Ie. 1 piece of paper granting access to records for that person, not each place has a different form for him to sign), process changes (documents which can be legally accepted at every place) and electronic development (a single stop database for all mental health, housing, counseling food etc.)

Lastly, I would like to point out. If we did not have to pay so much of our income to taxes, so they can support programs a young white male can not qualify for, we would not need these government programs. The more taxes we have to pay, the less we will be able to “help ourselves” (our own families).

I propose instead of a 3500.00 per year write off/deduction for dependent children, how about a SSI tax forgiveness kind of program. If your adult child manages to get on SSI, we as parents should be able to help them by contributing to housing expenses. I would much rather forgo paying taxes and instead pay for a safe place for my son. Instead, we pay $59K between FICA/Ca State / Federal taxes, to programs that are going insolvent or my son can't use because he doesn't "qualify". That does not leave any wiggle room in helping our own son with his living expenses. It should be dollar for dollar removed from the amount we pay in taxes. We COULD potentially afford to keep our son from being homeless.

My question for you is where do we start?

Response 26:

Dear Chairman Wyden,
Dear Senators,

I want to express to you the importance of changing several of the laws concerning seriously mentally ill people. My son who is 34 now was diagnosed with schizoaffective disorder when he was 22. It has been an extremely long road because he has little insight into the fact that he is seriously ill. I will be short with the story but he went homeless A couple of years ago. He then stole my car. I had to have him arrested and jailed in order to get him off the streets and hopefully get some help. They could not determine that he was confident after four months and sent him to another program to try and make him conpedent. But that didn't work either so they sent him to the mental health facility. There they gave him the care that he needed and placed him on the proper medication's.

But tell me why I had to get him arrested and jailed for months to get him help. If he had had a heart attack, stroke, cancer etc. he would've received the help he needed. But instead we send them to jail. The HIPPa law needs to be changed for those who have seriously mentally illness. We cannot advocate for them when we cannot receive any information from the doctors and nurses involved in their care if they are hospitalized. There need to be more hospital beds available and we need to treat those who have serious mental illness the same as if they were having a heart attack, cancer, car accidents. We would not have them sit on a gurney for hours in an ER and then send them home. We need to find better treatment and that is redefining some of the laws that affect the seriously mentally ill. The treatment advocacy center has described to you many of the things that need to be addressed and I support them wholeheartedly.

Please help those with serious mental illness and help those family members who advocate for them.

Response 27:

Dear Chairman Wyden,
15 years, 20 + Baker Acts, 1 Marchman Order, 2 short-term Residential Stays, 3 short-term Partial Hospitalization Stays and countless hours of outpatient therapy and still not well. Because our loved one does not recognize her mental disease and is an adult, it is almost impossible to get and keep her in treatment. With AOT she could have been court ordered into OUTPATIENT treatment and avoided much of this, and we could have saved thousands of

dollars. AOT can require long-term consistent treatment which is needed to see results in serious mental disease in particular. For some reason, Drs resist this. There needs to be more awareness of this provenly succesful treatment.
The patchwork of our mental disease system doesn't allow for the consistent long-term help she needs.

Response 28:

Dear Chairman Wyden,
Thank you for seeking input on solutions to reducing barriers for SMI care, though it is tragically too late for my beloved son, [redacted]. My son was brilliant, a poet, and never hurt anyone in his life, yet horrifyingly became a homicide victim inside the New Haven jail 2 years ago at the hands of staff. Here in CT there is no assisted outpatient treatment (AOT) or community services for criminal justice diversion for those with SMI, especially when co-occurring self-medication misuse and anosognosia are present. My beautiful son with bipolar disorder had a handful of nonviolent misdemeanors - mostly nonviolent breach of peace when ill. The diversion offered was the command from the judge to 'get into a hospital for 3 months'. Impossible. We tried every way imaginable for a year to accomplish this in CT, finally borrowing $36,000 for an out of state hospital that discharged him early on a severe sleep apnea medical discharge after 2 months.
My son had to serve several months in the local jail, where he was accidentally (we believe) killed by corrections staff after calmly refusing to get up off the shower floor. Excessive, tortuous pepper spray, militarized staff, abusive restraints in a solitary cell and a brutal lieutenant appear to have all combined to cause his homicide. While one lieutenant was convicted of assaulting my Robby bear, and there are additional claims pending, nothing can bring our son back! Our nightmare will never end - and our devastation is only helped in knowing that we can work together to remove these horrible barriers to treatment for others!
I've read TAC's evidence-based solutions letter, and so many of these would have saved my son's life ensuring treatment before tragedy - but I focus on AOT and community programs to divert those with SMI out of the CJ system. This is the most cruel intersection of two very broken systems. Robby has paid the ultimate price, and we will never stop working to fix the inhumanity that cost him everything.
Thank you and bless you for working for a solution.

Response 29:

Dear Chairman Wyden,

I write you today to beg for a change in the way persons with serious brain disorders are treated in the United States.
No family should have to suffer the horror of watching their loved with a neuro-degenerative brain disease, like schizophrenia be deemed a criminal before receiving adequate medical care.
Please consider implementation of the following:
1. The IMD Exclusion must be repealed!
2. Repeal the Medicare 190-day lifetime limit, yet another glaring example of the blatant discrimination against those who suffer from these chronic illnesses.

3. The provisions of the 21st Century Cures Act provided key steps needed to increase integration, coordination and access to care. Congress should re-authorize the 21st Century Cures Act and forcefully implement and enforce all the provisions of the Act.
4. The 21St Century Cures Act requires the Department of Justice and others to collect and regularly report data involving law enforcement encounters and mental illness and this requirement must be enforced and funded including the creation of a national database for law enforcement use of force, including the role of mental illness. Federally mandated and funded demographic data collection should include race and ethnicity information. Policymakers and stakeholders need better information to better inform policy decisions affecting funding and equity.
5. #HIPAAHandCuffs must be removed from family members, significant others who are often the sole providers of care for people living with SBD. Current HIPAA laws are not enough to allow family/caregivers to be a participant in their loved ones treatment. Nor are we allowed to know when our loved one is released from a hospital, care facility, board and care facility, etc… We would not exclude family members from being allowed to know where their loved ones with Alzheimer’s or Parkinson's Disease were or to participate in their loved ones treatment plan. We are responsible for and desperate to provide their care, including medications, yet we are not even allowed to know what their medications are or when their next appointment is. Our children go missing, are left on street corners after being discharged from a hospital, or, worse, greyhounded to a city across the country, without our knowledge.
6. Assisted Outpatient Treatment (AOT) must be federally mandated! If you truly want to improve access to care, you must understand that, If an adult recognizes their illness and the need for help, they can voluntarily seek out treatment for themselves. However, in the case of serious brain illnesses, the person often does not recognize their illness (anosognosia), does not seek treatment, and will actively resist any attempts to bring them to access treatment.
Anosognosia is the number one reason why up to 50 percent of those with schizophrenia and 40 percent with bipolar disorder refuse treatment. AOT paves the way for them to receive that treatment. AOT is evidence-based, compassionate care, allowing those afflicted with serious brain disorders to live in the community with the best chance to recover from their illness, becoming productive members of society.
6. Laws requiring dangerousness before a person can be treated for serious brain illnesses must be repealed and replaced with a national standard allowing for anyone who, by virtue of the severity of their illness, lacks the capacity to know they are ill, to receive treatment. We would not leave someone suffering from a heart attack to die in the street. People with SBD deserve the same access to treatment.

Response 30:

Dear Chairman Wyden,
My son has a Serious Mental Illness whose psychosis is so severe that he needs intense treatment in a housing environment. IMD settings could provide care that he needs without a set time limit. Please remove the IMD restriction for those with a Serious Mental Illness like has been done for Substance Use Disorders.

Response 31:

Dear Chairman Wyden,

The Broken Jaw

If you are a danger to yourself or others you can get help. That help can be a two edged sword. It depends on what hospital they take you to, the type of insurance you have, and what the police report that likely you brought you there says. My son once landed at Augustus Hawkins in Los Angeles. The herding of those with varying degrees of hallucinations and psychosis in one arena is a recipe for disaster. Hospitals designate intensive care units for the most ill and jails sequester the most violent offenders. In hospital psychiatric wards there seems to be no distinction in diagnoses or treatment. My son who was stabilized shortly after arrival is a personable and loving individual. Staff at the many hospitals he has been to always comment about his character. I am always grateful when others can see past the mask of his mental illness and see the heart of who he is. When he told me there were gang members in the unit he was being treated in I was concerned. I justified in my mind that he'd be safer there under 24/7 supervision than in the streets where someone could assault him out of fear or have a run in with a police officer who might fail to protect and to serve him. I cannot express the pain I have everytime I recollect the phone call I got that he had been violently hit in the jaw by a new resident and that it was broken. You have to know that this pain was nearly unbearable because this was the second time. My beloved son just a few years before had been ejected from a car onto a freeway and had suffered near fatal injuries with numerous broken body parts. Pelvis, jaw, ribs, etc. and now he had been assaulted. I still remember meeting him at the wee hours at the county hospital for the surgery to repair his jaw. He was accompanied by two staff. He was wearing an orange jumpsuit and his feet were shackled. He looked every bit the criminal and yet he was a victim. I am reminded of his pain and mine everytime I look at his face that has lost its symmetry and the once perfect smile with teeth misaligned, and his continued cry, “These places aren't good mom.”

Sick and Released

I can't describe what it is like to ride in a car for miles with a psychotic person. My son commandeered the radio and turned it up as loud as it would go, he demanded that I not change it and wanted to know why I was tearing up. He had been discharged from a psychiatric hospital. A hospital whose doctor failed to return my calls and used HIPPA regulations for cover. My insurance had allowed him a definitive amount of time irregardless of his progress or stability and he had met it. He rocked in his seat vigorously, and I tried to figure out what I was going to do. Where could I go with him in his state? He has a sister at home who used to be a straight A student. She used to be many things. I have already had to defend my right to fight for and support the son I bore to the authorities. My husband and I were shocked the night Child Protective Services made an unannounced visit to our home. I am a teacher and mandated reporter and here I was being investigated for failing to protect my own daughter. If my son had cancer or some other unimaginable disease we'd have the empathy of outsiders, dinners would be dropped off, and he would never be discharged mid treatment. No one would assume that he was violent. We had to explain to social workers that he deserved the same level of devotion and safety of a home as anyone else. The case was dropped and neglect unfounded. I cannot say the same for the many hospitals that leave families to figure out what to do with children we love who are released unwell and prone to further deterioration. They put the mental health and stability of those who love and support them at risk. The trauma my daughter suffered by being a witness to her recently released brother's behavior while repeatedly having to leave her home to go stay with a relative while I tried to manage his symptoms, has had long lasting effects on all of us. Ironically we were able to get therapy for her while her brother's needs were outside of the scope of their treatment! He could get prescription drugs but no therapist.

The barriers to treatment start with the absence of supportive living environments. A live-in supported home modeled after the system for those with developmental disabilities would prevent the cycling through failed mental health programs. They would have the support needed to remain med compliant, engage in their communities, and be productive citizens.

The barriers to treatment include the absence of science based therapies and the reliance solely on pharmaceuticals. The treatment centers fail to treat the individual and apply a one size fits all remedy. Diet, environment, and therapies are wholly disregarded and there is no high standard of treatment that facilities are accountable to uphold.

The barriers to treatment start with the absence of information and collective resources given to parents who find their loved ones experiencing their first psychotic break. These young men and women age as they cycle through a system that half heartedly responds to their needs and rebuffs the parents that support and advocate for them.

We must focus on preventative measures and holistic treatments if we ever hope to stem the tide of human loss.

Response 32:

Dear Chairman Wyden,

I am the mother of a son with the Serious Mental Illness (SMI). Schizoaffective Disorder. He has spent most of the last 5 years - since his first breakdown - addicted (self-medicating), homeless or incarcerated. The very core of the homeless humanitarian crisis is SMI. This population "self-medicates" with meth and heroine (easily obtained and cheap on streets) because family members, case workers, law enforcement and doctors can only stand by, helpless due to outdated, misguided policies a 1/2 century old.
Current Commitment / Conservatorship policies make it all but impossible to usher individuals like my son - who are suffering a tragic brain disorder and dire living conditions - into involuntary treatment which we know can help restore them to a life of productivity, relationships and hope - and off the streets and off street drugs.
I support all of TAC's recommendations, and I desperately urge you to do what is in your power to provide new policies that will allow family and professionals the directive of committing diagnosed SMI to involuntary treatment - before inevitable tragedy.

Response 33:

Dear Chairman Wyden,

Request a Government Accountability Office (GAO) report on the extent of psychiatric boarding in emergency departments in the U.S.
My sister, Cynthia Wasserman, was never treated for mental illness. She was hospitalized for back pain which turned into metastatic breast cancer in the fall 2020. She was not receptive to any assistance for mental health. She is not independent now and cannot find housing. She was released from the hospital to a rehabilitation facility who basically suggested a homeless shelter. There were 0 options. Even the local ombusdman was unable to assist. Even if her mental illness had been treated, there were still no options for housing. This has put an insurmountable amount of stress on my family and my household. If there were more housing resources, I believe that this situation could have been impacted in a positive way. Thank you for your time.

Response 34:

Dear Chairman Wyden,

My disabled adult son was totally out of control. He has assistance from the APD who did not help. I tried the police and other mental health agencies who refused to help. After I filed my own ex parte order he ended up in a mental hospital. Then I discovered a new organization called Centerstone. They helped out when no one else did. He has a counselor, several nurses, etc. and is on his way to recovery. Please provide better mental health care for all. Nothing has changed in 44 years since living in Fort Myers. No one should have to struggle to save their child in a mental health crisis.

Response 35:

Our daughter had her first break from reality 14 years ago while in her first year of law school. Since that time she has been hospitalized at least a dozen times, from a few days to a month or more. Diagnosis is Schizophrenia. She has lived in multiple places, some by choice some by mandate (conservatorship) including Board and Care homes, Room and Board homes, with family or friends, Recovery and Wellness Centers, and Transitional-Houses and all of them temporary. Currently the only housing available to her given her SSDI allowance, is a Room and Board, with minimal support, where she shares a room with two other women. With lack of insight into her illness and lack of support, her level of care needs can not be met and do not allow her to make progress toward wellness. This pretty much insures that she will continue to cycle through non-standard housing, hospitals, and finally the street. Neurological disorders such as Schizophrenia should receive an equitable level of support and quality of care that individuals suffering from Developmental Disorder and Autism receive.

Response 36:

Hello,

I have tried to support my son's severe mental health for over 20 years and the money is running out. I am getting too old to support him.. To get support services they view my son as one of the lucky ones, so the county programs see him as "housed". He would need to become homeless to get support. Also, the programs are so disjointed that support becomes very difficult if not impossible to coordinate....Why is it possible for the Developmentally Disabled to get support services but not so for the Severely Mentally ill? Why is there such discrepancy? Can you understand that jail and emergency room visits and homelessness are more expensive than support?

Please hear my voice. My son deserves to live in a decent place but housing alone will not solve the issue. Support services are required in conjunction. I would love to organize a group of families together to create a decent place for him to live with others with similar conditions but getting the support services is the great roadblock. They are simply unaffordable.

Please help the SMI population. It will go a long way towards solving the homelessness problem in our cities.

Response 37:

Dear Chairman Wyden,
Our oldest son, was diagnosed with schizophrenia as a sophomore in college. He had a successful high school experience complete with music, sports and academic achievements. He was admitted to the University of Virginia and started having difficulties. I can’t impress on you how much work we put in to trying to get him help or how high a price we paid psychologically and financially. His illness took a text book course, and homelessness, arrests and hospitalizations followed. He has been on at numerous medications. These med trials, while he lived at home, involved everything from depression to impulsivity with no inhibitions. We tried to keep him and out family safe. We didn’t want our problems to become the neighbors’, the nearby businesses or community’s problems, frequently they did. We searched for a facility that would take him and get him the care that could start to heal him and kept coming up empty handed. Instead, he had short-term hospitalizations that medicated him till he was compliant, then he would be released only to stop his treatment. He had no comprehensive diagnostics or treatment. We routinely got advice from well-meaning people on how to help him. The only analogy I can come up with is if we had a person with broken legs in the middle of the street would we say to them” if you really wanted to get treatment you would walk out of the street?” That person has broken legs, our son has a broken brain.
That was eight years ago and I am happy to say he is living at home, working part time through a state supported employment program and a participating in treatment client with our state’s Colonial Services Board, Program of Assertive Community Treatment (PACT) team.
We are at this particularly stable time because of a few key things. Our son, when he was ready, was able to be have a same day appointment at our Colonial Community Services Board here in Virginia while he was extremely symptomatic. Virginia expanded our Medicaid eligibility so that he could afford care. The Virginia court system required him to have treatment (AOT), and our son was able to get into the PACT program with a team that came to the house. And we think one of the biggest parts is that he is now on an underutilized medication called clozapine. this along with all the psycho social support from the PACT Team, family and friends has brought our son back to starting to be asset to the community not a liability. One of the organizations that became essential to us was the Treatment Advocacy Center. We are in

agreement with their following recommendations to the Senate Committee on Finance, to eliminate barriers to treatment in particular :

- Repeal the Medicaid Institution for Mental Disease (IMD) exclusion
- Expand federal funding for assisted outpatient treatment (AOT)
- Require the National Institutes of Mental Health (NIMH) to establish transparent and peer-reviewed standards for estimating prevalence rates for schizophrenia in the U.S.
- Mandate periodic NIMH prevalence studies of schizophrenia, bipolar disorder, and other severe mental illnesses at regular intervals, and explicitly require that prevalence rates be accurate and comport with peer-review protocols
- Fund programs that are tailored to community resources and divert people with SMI away from criminal justice involvement to the greatest extent possible

Response 36:

Dear Chairman Wyden,
My daughter has schizophrenia and is delusional and psychotic. She would have to be at risk of harming herself or others in order to receive treatment at a hospital but I feel that's too late. She should receive treatment now due to her psychosis. In August she broke into an arts non-profit because she thought she worked there and had to set-up for an event. The police drove her home and there is a warrant out for her arrest but despite filing a petition to probate court I can't get her treatment because there are over 80 people ahead of her and not enough beds in Bryce, Alabama's state hospital ,and Birmingham hospitals. A good program for her would be assisted outpatient treatment--a court ordered treatment plan after she left the hospital and returned to the community. This type of program would decrease hospitalizations, homelessness, violent behavior, victimization and substance abuse and decrease public funds. Just think how this would improve the quality of life for everyone in our cities!

Response 38:

Dear Chairman Wyden,

When an adult SMI person is placed in a hold or in jail, their loved ones are not notified. So, we can't help or have any say in trying to help them. Even though they are in the system and there many proofs that they are not stable to make any kind of health decisions. They might sound coherent, but there wouldn't be so many SMI people on the street, jail and in hospitals if they could make good choices or decisions for themselves.

There must be an easier way to apply for conservatorship besides the doctor in charge when they are placed on a hold. Many times, we do not know that they are being held and here in California it is almost impossible for the police to have them transferred to the hospital unless they are literally hurting themselves or someone else. Why does it take "to commit a crime" to get our loved ones hospitalized? And 72 hours does not stabilize them, they put back on the streets with no medicine and no further checkups at any level.
Some kind of a Tier system should be implemented; depending at where they are in their recovery to keep them medicated and off the streets.

Please help families like mine!

Response 39:

Dear Chairman Wyden,

Dear Senate Committee on Finance,

I am writing to you today, because my sister lives with schizophrenia. I am well aware of the numerous barriers to care for persons living with severe mental illness (SMI). I was blocked by the HIPAA privacy law from getting my dear sister help, when she was starving herself. Her healthcare proxy did not believe in mental illness or medication. It was a nightmare. Finally, after months they had to get her some help. She was hospitalized weighing 70 lbs.

I was finally allowed to move my sister from Massachusetts to a good facility near me in San Francisco. She is on medication and gained weight. But there is no cure for schizophrenia.

Along the way, I went to National Alliance on Mental Health (NAMI) support groups and took their Family 2 Family class. It was informative. The stories I heard from family members was gut-wrenching. In an effort to make a difference, I am currently working on a documentary, Piece of Mind, that tells the story about the struggles for care in a failed mental health care system and promotes humane solutions.

In my research, I found these issues that need addressing and improved up-to-date laws, from the outdated archaic laws that limit help for persons with SMI. Below are what I have discovered need to be changed.

Individuals afflicted with Alzheimer's or autism are not put in jail, or left to wander the streets. They receive a bed and care. The same needs to be done for persons with SMI. 50% of individuals unaware of their illness. They need your help now!

Thank you for your concern. I look forward to hearing that comprehensive humane changes have been made to address the crisis of persons living with untreated severe mental illness.

•Repeal the Medicaid Institution for Mental Disease (IMD) exclusion
•Repeal the Medicare-190 day lifetime limit
•Expand federal funding for assisted outpatient treatment (AOT)
•Establish a national database of psychiatric beds in the U.S.
•Request a Government Accountability Office (GAO) report on the extent of psychiatric boarding in emergency departments in the U.S.
•Require the National Institutes of Mental Health (NIMH) to establish transparent and peer-reviewed standards for estimating prevalence rates for schizophrenia in the U.S.
•Mandate periodic NIMH prevalence studies of schizophrenia, bipolar disorder, and other severe mental illnesses at regular intervals, and explicitly require that prevalence rates be accurate and comport with peer-review protocols
•Fund programs that are tailored to community resources and divert people with SMI away from criminal justice involvement to the greatest extent possible

•Include emergency responders with knowledge and experience with SMI— including but not limited to schizophrenia, bipolar disorder, major depression, and other psychotic disorders—in both the planning and implementation of any emergency response models
•Enforce the bipartisan language in the 21st Century Cures Act that requires the Department of Justice and others to collect and regularly report data involving law enforcement encounters and mental illness
•Include racial and cultural demographic information in any data collected to inform future funding and policy decisions related to the treatment of mental illness, as well as reform efforts to prevent and reverse criminalization of SMI
•Make permanent all telehealth coverage for Medicare recipients that were expanded under Section 1135 authority during the COVID-19 public health emergency

Response 40:

Dear Senator Ron Wyden, and other members of the Committee on Finance:

This is in response to your request for input from stakeholders to help you better understand how Congress can address behavioral health care challenges.

First, thank you Senator Wyden, for keeping at it. I'm sure you don't remember, but back in the late 1990's you intervened for my son who was delusional and psychotic in Oregon. He died in a California hospital psych ward in 2014. He never did receive the help he needed for schizo-affective disorder. In the interim, I became a mother bear and mental illness activist. I've written two award-winning books, Sooner Than Tomorrow — A Mother's Diary About Mental Illness, Family, and Everyday Life (Nautilus Book Awards Gold Medal Winner, Memoir, 2019) and Tomorrow Was Yesterday, Explosive First-Person Indictments of the US Mental Health System — Mothers Across the Nation Tell It Like It Is (Nautilus Book Awards Silver Medal Winner, Social Change, Social Justice 2020). The second book includes stories from 65 mothers from 28 states, and a fifteen-point plan to address serious mental illness (SMI - schizophrenia, schizo-affective disorder, bipolar disorder, clinical depression, etc.). The plan was developed in 2019 by advocates/activists from across the country.

In January 2020, 150 Tomorrow Was Yesterday readers, from every state in the nation, volunteered to send a copy of the book to the White House (Joe Biden, Jill Biden, Kamala Harris, Xavier Becerra, and individual legislators) thinking 150 copies of the same book from every state might get someone's attention. Five months later, we all began receiving form letters from the White House thanking us for our "gifts" and for welcoming Joe Biden to the Presidency. No mention of the topic. No reference to the books. It was hurtful and insulting.

The 15-part plan was prioritized by the participants. The number 1 priority on their list is to "Reclassify Serious Mental Illness (SMI) from a Behavioral Condition to what it is, a Neurological Medical Condition." Until we look at SMI through a biological/physical lens, the significant changes we users of the system need will not happen.

I'm not trying to specifically address the questions you've posed in your letter. The SMI Plan cuts through all of them. More significantly, it raises issues not included in your list. The suffering in the SMI community (11-13 million diagnosed individuals plus their families) is intense. We're screaming to the heavens for help. So far, no one seems to be listening.

Summary from Tomorrow Was Yesterday:

"As it stands today, the US mental health/illness system is filled with political landmines and gut-wrenching divisions: parents vs. children, peer organizations vs. family organizations, voluntary vs. involuntary treatment concepts, psychiatrist vs. psychologist turf wars, state vs. federal jurisdictions, HIPAA restrictions vs. parental rights, lack of beds vs. incarceration, unions vs. providers, psychiatry vs. anti-psychiatry, civil rights vs. dying with your rights on, NIMBYism vs. housing, traditional medicine vs. holistic medicine, and funded advocacy organization vs. unfunded grassroots advocacy efforts. I watched my son Pat die because the system is tied up in bureaucratic and philosophical knots."

I would be happy to send you a copy of Tomorrow Was Yesterday which includes the 15-point plan to address SMI. My hope is that you, and others on the committee, might read our stories, take the plan seriously, and pursue some of its recommendations. It's a beginning. It's from the people in the trenches -- the sufferers, the families, the folks the system is supposed to help.

Thank you for reaching out. Let me know if/where I should send a copy of Tomorrow Was Yesterday.

Response 41:

Dear Chairman Wyden,

My daughter has been diagnosed with schizoaffective disorder and has been hospitalized numerous times. We have discovered over the years that it is almost impossible to get help until there has been a crisis. A year ago we reached out for help because our daughter was being tortured by psychosis. We were told her illness was not severe enough (yet) for hospitalization. A day later she had a serious suicide attempt and ended up in the ICU for two weeks. This past year she had another psychotic break and was in the hospital for a month. There was no aftercare when she got out and we are very worried. She wants to work and be independent. Unfortunately there is no help or resources to make that possible. As her parents we try to help as much as possible but HIPPA and the laws make it extremely difficult.

People with severe mental illness need help with housing, healthcare, and support. Not providing help leads to homelessness, prison and death. Providing support is more humane and would actually save money for society.

We need more research funded to provide better care for people with severe mental illness. People become ill in the prime of their lives and suffer terribly. Research and better treatment would help people suffering with severe mental illness to become functioning and productive members of society. This is what my daughter desires more than anything.

Response 42:

Dear Chairman Wyden,

My daughter was 16 when she first experienced a major depression and psychotic break. She spent 26 hours in a crisis center with no sleep in bright lights and lack of compassionate care. She had to wait that long before they could find a bed for her at an inpatient hospital. In addition, it was a Friday when she was finally admitted. Little care happens on the weekend. Since she was 16, we were unable to get information about what was going on once she was at the hospital. There needs to be a better way to get parents access. Our daughter did not understand what was going on and had no idea how to give us access to her information. She signed paperwork on her own and didn't understand what she was doing. It was a traumatic experience for all of us.

Response 43:

Dear Chairman Wyden,

Investigate tri county cap guardianship for embezzlement of clients social security benefits for company operating costs to amount of 375,000 not enhancing quality of life but diminished maintaining fraudulent disability diagnosis Sincerely Pamela soucy c/ o Nicole soucy my daughter stuck in NFI transitional housing programs administrative support staff incompetence mishandling clients social security benefits for profit

Response 44:

Dear Chairman Wyden,

As part of NAMI (National Alliance on Mental Illness) I have learned a great deal to help me and my family deal with my adult child who suffers from schizo-effective disorder. There is no federal or state help for families and we end up feeling helpless otherwise. My son was diagnosed while in college and already I had no rights as a parent to intervene on his behalf without his consent. In this timeframe, my son has been hospitalized twice, the first time was involuntary and the second was voluntary. He was treated however there really is no follow-up. While it is understandable that we want to protect the rights of individuals, it really makes no sense that we expect a mentally ill person to make rational decisions regarding their healthcare and maintaining a job. I can afford to pay for private psychiatrist and therapist temporarily, but this model can not be sustained permanently. My son has not been able to work for 2 years now and the pandemic and even when he was working, it was only part time work with NO BENEFITS. There are no mental health professionals in my area who have availability and will accept the government funded insurance. I tried for months to get one and when my son was willing to get treatment again, I had to make the choice to pay for it personally. Most people I have met through NAMI are unable to pay privately and I really feel for them. Even when you get your loved one into a hospitalization, there is no real follow up afterwards and the cycle starts all over again. When I am gone, I have no idea what will happen to my son if he does not get well and take care of himself.
I fully support and hope you will too these recommendations.

- Repeal the Medicaid Institution for Mental Disease (IMD) exclusion

- Repeal the Medicare-190 day lifetime limit
- Expand federal funding for assisted outpatient treatment (AOT)
- Establish a national database of psychiatric beds in the U.S.
- Request a Government Accountability Office (GAO) report on the extent of psychiatric boarding in emergency departments in the U.S.
- Require the National Institutes of Mental Health (NIMH) to establish transparent and peer-reviewed standards for estimating prevalence rates for schizophrenia in the U.S.
- Mandate periodic NIMH prevalence studies of schizophrenia, bipolar disorder, and other severe mental illnesses at regular intervals, and explicitly require that prevalence rates be accurate and comport with peer-review protocols
- Fund programs that are tailored to community resources and divert people with SMI away from criminal justice involvement to the greatest extent possible
- Include emergency responders with knowledge and experience with SMI— including but not limited to schizophrenia, bipolar disorder, major depression, and other psychotic disorders— in both the planning and implementation of any emergency response models
- Enforce the bipartisan language in the 21st Century Cures Act that requires the Department of Justice and others to collect and regularly report data involving law enforcement encounters and mental illness
- Include racial and cultural demographic information in any data collected to inform future funding and policy decisions related to the treatment of mental illness, as well as reform efforts to prevent and reverse criminalization of SMI
- Make permanent all telehealth coverage for Medicare recipients that were expanded under Section 1135 authority during the COVID-19 public health emergency

Response 45:

Dear Chairman Wyden,

I have a 54 page report written on how to fix this and why it needs done!!!!!!

I've LOST 2 brothers to suicide bc NO HELP

I've had my daughter sent home after suicide attempt bc LCH does not understand!!!!
I've waiting a year finding a psychiatrist while my daughter was in psychosis!!!!
More beds are needed
More training is needed
More education for teachers to understand mental health issues as it is NOT Urgent Care centers JUST for mental health

I have a 54 page report written that I can send.

Response 46:

Dear Chairman Wyden,

To whom I may concern. I am a 48 year-old twin who has witnessed my sister battle schizophrenia for 25 years. She is in and out of shelters, rooming houses or in the street. She has little access to treatment because the law states that she can remain I'll as long as she doesn't harm anyone. Often she is suicidal. She's been in Dauphin County Prison on occasion. The times that I advocate to get her services I am told she has to ask for it. She is too sick to ask. She is fearful of everyone. How can she ask for something when her own mind is against her? Please advocate more trust and power of attorney access to family members so that we can speak on behalf of our loved ones. I just want my sister back and I haven't had a healthy relationship with her for decades. Thank you.

Response 47:

Strengthening the workforce – The Infant/Early Childhood Mental Health (IECMH) workforce is a specialized and necessary one. The Senate must invest in the IECMH workforce and establish the IECMH clinical workforce development program introduced in the RISE from Trauma Act.

Increasing integration, coordination and access to care – I know first hand the value of mental health consultation across settings including child care, home visiting, early intervention, primary care, and child welfare, as well as integrated behavioral health in pediatrics, obstetrics, and family health settings.

Improving access to behavioral health care for children and young people – Infants, toddlers, and young children need to be served, and they have a right to developmentally appropriate services that meet their unique needs! Caregiver mental health, including perinatal mental health, is essential.

Ennis C. Baker, MSW, LCSW, Early Childhood Mental Health Specialist & Board Member, North Carolina Infant/Early Childhood Mental Health Assoc.

Response 48:

Dear Chairman Wyden,

It is critical to meet the IGNORED needs of the SMI population - it should be #1 priority for Congress in addressing mental health/illness issues!!!
My son, with bipolar 1, was denied a bed for inpatient psychiatric care near us and shipped to an available bed 3 days later, 1 1/2 - 2 hours from our home.
NIMH research should be focused on treatments for BP illness that help people TODAY. There should be more beds - eliminate the IMD exclusion. Make involuntary treatment for this

population possible across the country - so those who cannot understand they have an illness get treatment early. You would never allow Alzheimer patients to be treated like the SMI are.
We need brain diseases, like bipolar, to be at parity in every way with other diseases. Do we put people with Alzheimer's in jail? NO.
It is less expensive to address these barriers and obstacles to care for those with SMI than than the current state: warehousing all these people across the country in jails/prisons and cycling through emergency rooms - its reprehensible.
Pay attention. Do your job. Make change.

Response 49:

Dear Chairman Wyden,

Where to start? SO MANY BARRIERS to treatment. My son is 38 years old and has had SMI since age 17. I suppose the biggest is getting the hospital/doctors to communicate with us when he is hospitalized. My son is interdicted but most times this legal document didn't mean much to staff. If the hospital staff does not ask family what is going on and just relies on the patient for this info then they will never have the full history. Unfortunately family support is rare in cases of SMI but in our case my son had family support but yet the hospital does not work with us in his treatment. Also most cases involve a 7-10 day hospitalization stay because of Medicaid or insurance guidelines. That is not long enough to produce a positive outcome. My son has been hospitalized over 25 times since his diagnosis. I have learned how to advocate on his behalf. Hurricanes here in southwest Louisiana had him displaced for over 14 months. This has been a huge barrier and concern. He is finally moving back to Lake Charles this week. Housing for the mentally ill is woefully inadequate. I could go on and on. Thank you for allowing me to have some input.

Response 50:

Dear Chairman Wyden,

My family member has severe mental illness. Severe mental illness is a medical disease. People with severe mental illness are suffering & need the medical treatment, understanding & compassion they deserve. My major concerns are: 1) Repeal the Medicaid IMD exclusion so there can be many more needed inpatient psychiatric hosp beds in every state. No state has enough inpatient psychiatric hosp beds. 2) Allow family members to have access & input regarding treatment. According to SAMHSA the HIPAA laws are used against family members of people with SMI but the HIPAA laws are not used in this manner with people with other medical conditions.(i.e within the same hosp ER Dept psychiatric ER Dept family members are denied medical information stating HIPAA laws while in other areas of the same ER family members are given medical information & there is no mention of HIPAA laws) 3) Many people with severe mental illness are in prison or homeless. Training is needed to divert people with SMI away from the criminal justice system & reform is needed to reverse the criminalization of severe mental illness. Thank you

Response 51:

Dear Chairman Wyden,

Severe and persistent mental illness (SPMI) has not received the focus that it's due since many mental institutions were closed back in the 1960s/70s, without adequate alternatives. There continues to be discrimination with the Medicaid Institution for Mental Disease (IMD) exclusion and the lifetime Medicare 190-day limit; these should be repealed immediately. Many people with severe cases of schizophrenia who continue to experience delusions despite medications may need longer stays in psychiatric hospitals. Right now, the appropriate alternatives are few or none. Government should be providing residential solutions similar to those available to people with intellectual or developmental disabilities (IDD) for those with mental illness who truly cannot care for themselves. Instead, these citizens often cycle through hospitals, jails, emergency departments, and/or homelessness, all costly to taxpayers and to the ill person in terms of potential recovery or stabilization.
My adult son has had a severe mental illness for about 20 years; his condition has deteriorated despite medication compliance, and yet, there is no government-paid residential program for which he qualifies. There are a few private-pay residential programs, but SSI covers only a small fraction of the monthly costs -- this is unaffordable for most. So the cycling continues. Residential solutions for those with SPMI are desperately needed. Please prioritize this population and their needs in your budgetary processes.
Thank you for your consideration.

Response 52:

Dear Chairman Wyden,

I am a 51 year-old survivor of schizophrenia. My first attempt at recovery failed, but now I am successfully living with my illness. I believe that with better services and less stigma, things can get better for many people. My most recent efforts at self advocacy have worked well. I believe that with a minimal dose of the medication, life and stress management, and a positive story, a person can do well. I live independently, work full-time, write and volunteer, and had some romance. Most people don't expect this from someone with schizophrenia. I hope things continue to get better! Thank you.

Response 53:

Dear Chairman Wyden,

Dear senate finance members and Senate Finance Committee, I have a 38-year-old son who has a serious mental illness through no fault of his own. His illness is not drug induced. He has spent the past six years revolving through hospitals and jails and homelessness. The main reason is that he has stopped taking his medication. He does not believe that he is sick. Countless times the police have been called for doing a welfare check. They would say that they could see that he was really sick but since he was not in an eminent danger of hurting himself or others they would not do anything. This only allowed his condition to deteriorate more and more. I feel that if he could have gotten into a program with AOT it would’ve helped. Our country needs to

standardize and to expand AOT to be at home 50 states. Person with a serious mental illness who does not even realize he is sick it’s court ordered medication, they need to enforce it. There is no continuum of care and when people in the Texas area get released from the hospital many times they go back to living on the streets are in their car. There should be a repeal of the IMD exclusion so that people who need help can get it. It is important to divert people from jails who are mentally ill. You wouldn’t put any other patient who has medical conditions in a jail where they squalor and their conditions become worse. There needs to be affordable housing that is supervised and subsidize for people of need. When my son was living out of his car in a grocery store parking lot, he was given a warrant and arrested three times for criminal trespassing. He was never given any type of paper or explanation as to what this was. In his mind he thought he was protecting the parking lot from intruders because he used to work at that location. One time he was released from the jail and less than 48 hours later got arrested since he did not realize that he was doing anything wrong. Instead of spending hundreds of thousands of dollars on illegal immigrants unlawfully coming into our country, we need to take care of those who have serious mental illnesses, including veterans and homeless people who are literally dying in the streets. There should not be any limits to the funding that you were going to give these people to help them. There should not be a lifetime number of days that they are allowed to seek help And be hospitalized if necessary. If people like my son had a supportive continuum of care house with supervision and or made to take your medication especially when court ordered, you would have less people being homeless and living on the streets.
Mental illness is a pandemic that has been ongoing for a long time. It’s time to take the right actions to stop it.
Thank you.

Response 54:

Dear Chairman Wyden,

My son, age 43, with Serious Mental Illness (chronic, more severe that most) has been dumped from many treatment programs into shabby apartments, halfway houses and the streets. He and others of similar severity absorb more public funds via ER's, hospitals, police, courts, jails, etc. than if we provided long-term, involuntary (locked/secure for some), humane, treatment-oriented housing. We should REPEAL THE IMD EXCLUSION and move funding from courts/jails to long-term TREATMENT, along with other recommendations by Treatment Advocacy Center.

Response 55:

Dear Chairman Wyden,

The system is as painful as the illness itself -- So broken, this system - broken adjective reduced to fragments; fragmented. ruptured; torn; fractured.
not functioning properly; out of working order.
Mental Illness
For anyone who has either "been there" themself or has watched a loved one descend into madness: it is not those people who need to understand just how "crazy" the treatment of the

mentally ill in our country is in the 21st century. Until you've seen it from the inside, most people will have no idea that a parent has no power to help a sick child who is over 18 years old. That the person who is "crazy" is given the responsibility of making decisions about his care when he is as divorced from reality as he has ever been. That the only way of getting any sort of treatment is to first assault someone or try to kill onesself or another person. The average person has no idea of the hopeless, helpless position someone with a mental illness and their family are put in by the very people who we hope will help. Who among us, particularly those in the medical profession, would walk by a person in pain, dying of cancer, without attempting to help? Who would send that person to jail to be locked up with murderers and rapists instead of to a hospital, where he would be given the medical treatment he needed? Who would suggest that no help could be given to him until he tried to kill himself or someone else? This is what happens to someone's son, daughter, mother, husband every day in this country.

I understand mental illness and the horrible state of care and treatment in the United States in a very personal and tragic way, how a First World country like ours could treat a beloved son as if he were a criminal, just because mental illness struck unexpectedly. Mental illness is an uninvited guest. It is the cruelest of diseases. And it could happen to your son or daughter. Where so many hundreds of thousands of families are. Alone, without help from the medical profession, the legislatures, the law.

But deep down, we really don't want to believe this is true. Because if we did, we would have to admit: It could happen to us. It could happen to me. And that is such a frightening thought that we quietly search for explanations to prove that the mentally ill really aren't like us and they somehow deserve the torment they suffer.

Response 56:

Dear Chairman Wyden,

Our son's urn sits on our shelf because I couldn't bear to put him in the cold ground with a cold stone as the only reminder that he had lived. He was a gifted, gentle and giving type young man. Before the age of 25, he was on two board of directors and taught at risk youth in a media arts program. For a few years we watched him withdraw but didn't know it was a sign of serious mental illness. Then our world crashed down when he had his first psychotic event and attacked us at home. The first responders came and he was charged with 4 felonies and a few misdemeanors and after an over night at the hospital, hauled to jail. Our pleas for him to get mental evaluation and help were blocked by the current laws in place. Eventually after an expensive legal helper, we could get him out of jail. He was not himself and needed inpatient treatment but none was available because of the felony charges the state had brought against him. I wish for one minute that the people responsible for these barbaric laws could feel the cold sweat and agony that we felt as his parents. The newspaper wrote about him like he was a monster and in the digital age that would follow him forever. It took 7 months to get him into the state hospital and only because we had to testify against him in court for a mandatory commitment. We were forced to speak against him to get help for him. I wish for one moment that the law makers would have been in my seat next to the judge, telling horrible things about their own son while he sits there in shackles. After his time in the state hospital, he was allowed to come home. He was not himself and even with the monthly injections, he was a shadow of his former self. Our son would not have any joy in life with the upcoming court case and over 40 years in prison likely. He planned his escape route and no one knew his plans. On Oct. 3rd he took his life and I found him on Oct 4th. Please make the laws change so others don't have to go through what we went through. Paranoid schizophrenia is a terrible brain disease and needs to be treated like MS, parkinson's and Alzheimer's diseases. All brain diseases should have the same treatment of hospital beds not jail cells.

Response 57:

Dear Chairman Wyden,

Hello. My son is 29 years old and has schizoaffective disorder - bipolar type. He didn't present with symptoms until later in his college experience, but was able to continue school and receive his degree in chemical engineering. He held a good job until about 2017 when he had to go on leave. From that time, he has been hospitalized in inpatient psychiatric hospitals at least seven times, with more trips to the emergency rooms - approximately six times for that. When he has to go by ambulance or police car to the emergency room, and then an ambulance between the ER and the psychiatric hospital, we have to pay for many transportation costs. My son had private insurance until sept 2021, and we paid many thousands of dollars to help with his care.

Based on the number of hospitalizations and the length of stays he has had in the last four years, he will run out of the allowable lifetime Medicare days in under fifteen years. He would be 44 and out of his lifetime allowance of inpatient psychiatric hospital stays. There is a state hospital, Moccasin Bend, but it is very difficult to get in as it serves a broad area.
My son is a smart and loving person, but this illness and the psychosis robs him of so much. He had a particularly visible last two episodes. He describes the humiliation as one of the worst parts of this illness. He wouldn't go onto our front porch unless it was dark bc he was so embarrassed that the neighbors would see him. He remembers that there was a woman crying during this event, and while he knows he didn't cause the psychosis, he still has to live with the consequences.
There is no cure for this illness, and it still carries a stigma with it. He will be dealing with the episodes and the humiliation, and voices that tell him that he deserves this and that he's worthless. Please help us to at least give him what others with physical illness are entitled to.

Response 58:

Dear Chairman Wyden,

We urge you to include new policies and funding to meet the long neglected basic needs of individuals and families coping with the tragic impacts of serious mental illness ("SMI"). By sharing our personal story, we hope that you will use this pivotal moment for public health in our nation to salvage the lives of families like ours, who live with the devastating, and draining, effects of SMI.

We write to you as parents of our twenty-nine year-old son with a current diagnosis of schizoaffective disorder. Sadly, he has been through the revolving doors of 35 hospitals in 15 years. His journey has been a nightmare for him, and the rest of his family and disheartened friends. Individuals suffering with SMIs and families, like ours, have been overlooked by public policy for 50+ years. As evidence, we highly recommend reading Dr. Ken Rosenberg's Bedlam or familiarizing yourself with the outstanding advocacy work by the Treatment Advocacy Center or Arlington, Virginia (www.treatmentadvocacycenter.org).

Both sources confirm the sad truth: public policy on behalf of the Seriously Mentally Ill is a disgrace. This shameful state of affairs is the result of long-term divestment in institutional support combined with a woeful lack of R&D investment in psychotropic medication (as distinct from profitable rebranding of older medications.) We know from personal experience: the need is urgent. Today, there are fewer 1/10th of the beds in state-run psychiatric facilities available for long-term care for the seriously mentally ill as there were in 1955 – while the US population has doubled. This slide in long-term care and investment and research on behalf of the seriously mentally ill must be stopped and reversed.

Our son's revolving door story is a perfect illustration of all that is broken with our system. The broken link is when patients are discharged from hospitals after short "stabilizing" stays, at which point insurance companies stop paying and the hospitals cease oversight of the patient. This short-sightedness is catastrophic.

Many SMI sufferers do not accept their condition, in fact this is a fundamental part of their illness. Hospitals do provide some nominal social services, but once discharged, patients are on their own. It is only a matter of time until the SMI sufferer is re-hospitalized and the cycle starts again.

There are viable solutions. For those who have sufficient capacity and insight into their condition, hospital- affiliated step-down programs can bridge transitions from hospitals to supportive housing. The idea of these programs - and it is critical to recovery for those living with SMI - is that patients are treated to a continuum of care following their hospitalization which will set them on a track towards living as part of the community, whether independently or in supportive housing. Further, supportive housing is woefully scarce in every city in the US. Funding for supportive housing is a necessity for this continuum of care to have any meaning. For those without sufficient capacity and/or insight, prescribed medication would ideally be compelled, rather than simply encouraged. The Treatment Advocacy Center has developed powerful arguments in this regard. Those who cannot viably live in the community independently should ideally be housed in safe, modern and humane caregiving facilities for the long-term. Please see Sisti, Segal and Emanuel "Improving Long-term Psychiatric Care: Bring Back the Asylum" (Journal of American Medicine, 2015), for well-developed arguments for restoring and rehabilitating psychiatric facilities.

These reforms would mean the world to millions of Americans dealing with SMI's, whether individuals or family members. They must not be left behind, as we Build Back Better. We hope you will agree.

Anything (and everything) that you can do to serve this painfully unfunded problem would be greatly appreciated by us, and honored by all.

Response 59:

Dear Chairman Wyden,

My daughter was diagnosed with a serious brain illness when she was 12. She is 19 now and stabilized on medication, most of the time.

Finding appropriate psychiatric care that accepts our insurance was close to impossible and we live in New York City.

Please raise reimbursement rates for Mental Health Professionals AND Direct Care Staff.
(Seeing a psychiatrist for $250.00 a week is prohibitive.)

Fund Loan Forgiveness Programs for mental health (MH) Professionals including psychiatrists, psychologist, MH counselors and therapists, and family practice doctors, Nurse Practitioners and Physician Assistants who get certified in Psychiatric Medicine.

Family members with a serious brain illness often time require 24/7 care.
(My daughter did for 3 1/2 years, she was in residential treatment, until the right medication combination was found) Therefore, fund Psychiatric Assisted Living Campuses with multiple levels of care from acute care with First Episode Psychosis Programs, to sub-acute care, to independent living, to supportive employment, etc. We have similar facilities for our elderly with Alzheimer's and Dementia. We could have these for adults with these different types of brain illnesses.

Thank you for your time.

Response 60:

Dear Chairman Wyden,

Our son has been diagnosed with Treatment Resistance Schizophrenia (TRS) and has had Neutropenia, Agranulocytosis, Catatonia, (which nearly killed him), then 65 ECT treatments for the Catatonia. After 15 drug trials, he has improved only 25 %. Many drs say he is the most sick patient they have ever cared for. Now his care will mostly fall upon our shoulders as he is being discharged after 400 days (not his first hospital stay either). This will be a 24 hour job, unpaid.

Our son graduated from college with Honors and was a Fulbright finalist. He came home 2 weeks after graduation and had his first AND only break because he has never recovered. Current medications and treatment do not work well, even for most people and this is the silent crisis. We are dealing with a opioid like moment. We need faster crisis response time. We need more beds, doctors, nurses and social workers. We need the HIPPA law to be modified so that when in this crisis, families can stay involved to help the medical teams best figure out how to proceed. We need better care in treatment hospitals, with hospitals that are safe. We need rehabilitation and recovery, with good quality outpatient programs. We need to have people counted. We need funding to research and find better treatment options, and even a cure!

Our son will probably never use his college degree to support himself. We will have to support him for the rest of his shorten life. No doubt, our own lives will be shortened. Thousands of families are in crisis just like us and there is little help. There is ONLY a revolving door in every State, of which is a nightmare from hell. This brain disorder should be reclassified as a NEURODEGENERATIVE disorder - not a psychiatric mental illness. We will experience the loss of our son well before he is physically gone, when he should be in the prime of his career.

We endure far less emotional, social, financial, medical, and spiritual support. We have to find legal support that other terminal illnesses don't require. We don't have the same family and friend support like those families who are dealing with cancer or Alzheimer's. I personally have had family with both cancer, dementia & Alzheimers and there is nothing comparable to TRS.

I beg you to help us with more funding for research without the bias of Big Pharma and better oversight so that we are't questioning their data. How can a Covid vaccine be developed in record time with the help of federally funded dollars, and yet we can't research and resolve this to find better treatments for Schizophrenia and all that comes with it? These people need to be counted...and ACCURATELY. They need to be treated with dignity and compassion and urgency, just as anyone with cancer, or a neurological condition.
How different is our son's brain illness to brain cancer or Parkinson's or Alzheimers Disease? Not much. Except those illnesses are funded......
Thank you for taking the time to read about our sudden nightmare. We are begging you to help save our son.

Response 61:

Dear Chairman Wyden,
Thank you to Senate Finance Committee Chairman Ron Wyden, D-Ore., and Finance Committee Ranking Member Mike Crapo, R-Idaho, for launching an effort to develop bipartisan legislation to address barriers to mental health care!
Modifying HIPAA laws to improve coordinated care for families with serious mental illness, specifically supporting the 21st Century Cures Act, Division B: Helping Families in Mental Health Crisis Reform Act of 2016 and Title Xl: Compassionate Communication on HIPAA would alleviate the largest barrier I have had with advocating for my son who lives with severe mental illness (SMI).

My son has serious mental illness, specifically a disability of BiPolar Depression. I petitioned for him to receive Assisted Outpatient Therapy (AOT), which he receives along with Assertive Community Therapy (ACT) due to noncompliance with recommended treatment plans.

Health care providers using HIPAA to not communicate with me when my son is in danger has been the biggest obstacle to him getting the help he needs. On his 14th hospitalization since Covid began in 3-2020, the social worker at Woodhull Hospital in Brooklyn refused to talk to me about applying to a program at Columbia Presbyterian, Second Chance, that specializes in treating people living with severe mental illness. I implored her to listen to me. I advocated on my son's behalf and reached out to the Patient Relation's office who spoke with that social worker. After the 15th hospitalization, 3 weeks after the 14th discharge, he was finally transferred to the Columbia program where he is on his way to recovery after multiple hospitalizations and incarceration prior to Covid, and a mere 15 since Covid began.

The imbalance of the NIMH's final plan for researching trials of new drug treatment for schizophrenia and bipolar disorder is another obstacle to treatment of those living with these brain diseases. The nearly $2 billion budget had only 2 trials to help this desperate group of people.

Yet another barrier is the lack of resources for quality care in the recovery of severe mental illness. It took my own advocacy against all odds to make the transfer from the 15th hospitalization to a program that would break the chain of "revolving door" or "frequent flyer" admissions to the various double locked psychiatric units of Woodhull Hospital.
"Far too often, individuals across the country struggle to access timely, quality mental health care and substance use disorder services…", Wyden and Crapo wrote.
It is time to break this record and develop bipartisan legislation to address barriers to mental health care!Thank you.

Response 62:

Dear Chairman Wyden,

In reading this information, it seems there are many issues on the table for Mental Health. We understand the issues to be equality for those with MH and SMI diagnosis. Mr. Sukis is in recovery and in his 20s to 30s needed many hospitalizations for treatment of his MH condition. Mr. Sukis reported that he initially needed hospitalization for several months and at least twice. As he accepted his condition and used medicine injections, he stabilized, however, he needed in and out patient care several times in his 20s to 30s. A 190 day limit for life seems very stringent as he required months and sometimes weeks to recoup. He was fortunate to acquire Vocational Rehabilitaion and complete further education and program. He then stabilized, but with occasional setbacks. He initially received SSDI, yet slowly stabilized into full time work. His SSDI benefits were removed and he continued to work with regular checks with the psychiatrist an job coach. This would not have been possible had only 190 days of inpatient care been available to him at the times he needed it. People with MH and/or SMI tend to have setbacks and periods of success which is not unlike any other illness. Individuals may need some inpatient care in order to recoup their skills. Thus to set a limit such as 190 days seems arbitrary and not medically sound. As we know each person with any illness may need times they are need to be hospitalized and then released. It is not something that can be measured by a specific number in a lifetime. In his lifetime, also what was of great assistance to him was having the support of Vocational Rehabilitation which provided training, job coaching, and direction on job placements. Some jobs, Mr. Sukis obtained without supports from Vocational Rehabilitation, but this was after initial supports were given. Again, on occasion, Mr. Sukis would go back to get a refresher form Voc Rehab and job leads. The Vocational Rehabilitation Program provided him with training, job success, and wages which contributed to his being a productive and integrated member of the community. We also have one adoptive son with MH issues who was not able to be diverted into recovery. Instead he has spent time in prison and he has accessed as much education and training as is possible in this setting. Had the courts understood his Mental

Health Concerns, he may have been diverted into a treatment and training program where he would have been able to develop and use job skills and complete his education outside a prison setting. We pray and hope, when he is done he will be able to sustain a job after being "taken care of" in what appears to us to be system that is not able to promote as much independence as possible. Lastly, MD (Mental Disease) should not be excluded. Mental Illness is an Illness like any other, although it cannot always be seen like other illnesses. People with Mental Illness should not be excluded from care. We would not exclude someone with a broken limb or cancer from care. It follows, Why would we exclude some one from care due to a Brain Based Disorder such as Mental Illness. Thank you for your sincere consideration, Respectfully Dawn and Steve Sukis

Response 63:

Dear Chairman Wyden,

We lost our son, John, to Bipolar Disorder October 4, 2018. John's death was preventable. He died because he lost all hope that we would be able to find help for him, and I am sorry to say that he was right, because the systems that are needed for those suffering like he did do not exist in our society.

• A link to a short version of his story is pasted in below these recommendations our family request for your consideration:
1. Repeal the Medicare-190 day lifetime limit 2. Mandate periodic NIMH prevalence studies of schizophrenia, bipolar disorder, and other severe mental illnesses at regular intervals, and explicitly require that prevalence rates be accurate and comport with peer-review protocols 3. Fund programs that are tailored to community resources and divert people with SMI away from criminal justice involvement to the greatest extent possible 4. Include emergency responders with knowledge and experience with SMI— including but not limited to schizophrenia, bipolar disorder, major depression, and other psychotic disorders—in both the planning and implementation of any emergency response models 5. Enforce the bipartisan language in the 21st Century Cures Act that requires the Department of Justice and others to collect and regularly report data involving law enforcement encounters and mental illness 6. Include racial and cultural demographic information in any data collected to inform future funding and policy decisions related to the treatment of mental illness, as well as reform efforts to prevent and reverse criminalization of SMI

• Link to John's Story --
https://docs.google.com/document/d/1ZkjnPsnq_qckCGcb_mFTtMZzCdbJMSoKRP4ekHdLPpM/edit?usp=sharing

Response 64:

Dear Chairman Wyden,

There are two major flaws in the Behavioral Health Care system (BHC) that lead to untoward outcomes

1) These conditions are medical and require a higher level and continuum of care. Most with "mental health issues" have a brain illness, brain injury (concussions, TBI) or brain damage secondary to a serious substance use disorder. Some have all three.

2) What happens over and over, is the BHC system itself says NO to the "difficult to treat" and "nonengaged client". (**please see BHC Milestones of Recovery scale -MORS they use to categorize clients)
They>> themselves refuse care that need a higher level and more secure setting. They say NO >> I'm not taking this "dangerous, difficult patient" without providing any alternative and without any repercussion. Its akin to the CJS saying NO to taking criminals that have committed serious crimes. >>>>This is the gap.

When the BHC system themselves says no, its a death sentence for the seriously ill. They dump patients, that are higher need, onto the community rather than shifting monies or budgets to care for these difficult clients. They twist Mental health laws to justify their actions, saying its "their choice to seek recovery", when they obviously lack the "decision making capacity" (DMC) to self direct their care (a more accountable measure than behavioral health's gravely disabled definition). Physical health care has a higher standard of care for brain disorders, and can be sued, when not providing a "continuum of care" for those that lack capacity.

BHC has hidden behind "a false interpretation of immunity" when it comes to those that are a "danger to others". They have not followed WIC codes that are designed to hold/protect clients from criminalization. Instead, without ANY DUTY TO REPORT (Tarasoff laws) they dump clients onto the community and subsequently the CJS to manage.

This is the gap.
The BHC system needs to be held accountable for this failed continuum of care.
Yes, its more expensive to hold clients in more secure settings because of "involuntary judicial costs", but the taxpayer is still paying for these same costs in the CJS.
The public is NOT spared this cost. Its just out of another budget.

Response 65:

Dear Chairman Wyden,

I support ending the 190 day lifetime limit for psychiatric care. My son has schizo-affective disorder, and when he breaks down, he .needs weeks of in-patient care to get back on track -- which he has been fortunate enough to achieve. However, each hospitalization is short, requiring repeated hospitalizations over a several month period.
Not having enough time in the hospital to stabilize is a barrier to full recovery. It is unfair to deny treatment to people with serious mental illness when hospital care is essential to recovery.

Response 66:

Dear Chairman Wyden,

My son, has had an enduring struggle with schizophrenia for over twenty years. Our experiences have been disturbing and discouraging. As his mother I have found the quality and availability of care sadly completely inferior to the care my husband has received for his hospitalizations for cancer and pulmonary disease .

Another very serious concern is that first responders, ie. the police and fire department personnel are ill equipped to handle these emergencies and frequently contribute to escalating the behavior of the seriously mentally ill individual in crisis. We need to train our first responders to respond appropriately for this population and keep people with serious mental illness out of jail.

When I share information with friends and family about the disastrous conditions for our SMI population, they find it ghastly and incredulous.

We need to treat our SMI population with the care human beings deserve and imagine that each individual who suffers with these illnesses could be our son, daughter, mother, father or a beloved friend.

- With that in mind I support the following: Repeal the Medicaid Institution for Mental Disease (IMD) exclusion
- Repeal the Medicare-190 day lifetime limit
- Expand federal funding for assisted outpatient treatment (AOT)
- Establish a national database of psychiatric beds in the U.S.
- Request a Government Accountability Office (GAO) report on the extent of psychiatric boarding in emergency departments in the U.S.
- Require the National Institutes of Mental Health (NIMH) to establish transparent and peer-reviewed standards for estimating prevalence rates for schizophrenia in the U.S.
- Mandate periodic NIMH prevalence studies of schizophrenia, bipolar disorder, and other severe mental illnesses at regular intervals, and explicitly require that prevalence rates be accurate and comport with peer-review protocols
- Fund programs that are tailored to community resources and divert people with SMI away from criminal justice involvement to the greatest extent possible
- Include emergency responders with knowledge and experience with SMI— including but not limited to schizophrenia, bipolar disorder, major depression, and other psychotic disorders—in both the planning and implementation of any emergency response models
- Enforce the bipartisan language in the 21st Century Cures Act that requires the Department of Justice and others to collect and regularly report data involving law enforcement encounters and mental illness
- Include racial and cultural demographic information in any data collected to inform future funding and policy decisions related to the treatment of mental illness, as well as reform efforts to prevent and reverse criminalization of SMI
- Make permanent all telehealth coverage for Medicare recipients that were expanded under Section 1135 authority during the COVID-19 public health emergency.

Response 67:

Dear Chairman Wyden,

Our son has schizophrenia and bipolar disorder. 10 years ago he was so sick that he required involuntary treatment, something called Assisted Outpatient Treatment (AOT). He needed this important tool for 8 years in a row. It saved his life. This gave him the ability to gain stability and heal. His cognition continues to improve with time and treatment. Most in America do not have this resource available, their sons and daughters end up homeless or go to jail because of symptoms of their untreated illness. Most in America don't have a mom who was able to advocate full time either. Our current managed care system is good for the majority of people with mental health issues, especially those who have insight and can walk into a clinic or hospital and ask for help.

About 40-50% of people with serious mental illness have Anosognosia and do not understand they are sick, just like someone who has Alzheimer's. However, our current mental illness system is not set up for this very vulnerable group of people. Yet, they use up a good majority of the resources in our hospital systems, jails, and homelessness efforts. Because of outdated policies like the IMD Exclusion, most in this group are left at the behest of our "treat, street, and repeat" mental health system.

Please prioritize the needs of the seriously mentally ill so they can have a chance at a meaningful life like my son. Btw, my son has been working at a part time job for over three years now. He also has insight and understands he has a mental illness and takes his medications. Please focus on the seriously mentally ill, so they can have a chance like my son. Please.

Thank you.

Response 68:

Dear Chairman Wyden,

I became unstabilized after I fell into the donut hole and could no longer afford the anti psychotic medication that was keeping me sane. I took off on a road trip, got pulled over for speeding and after a confrontation with police was hauled off to jail. I spent two months there - no psych meds until I was finally released and made my way back to Orlando from the Tallahassee area.
I had hoped to be taken to a psychiatric hospital where I would have received treatment instead of punishment.
The proposals of diversion away from the criminal justice system for the mentally ill need to be implemented.

Response 69:

Dear Chairman Wyden,

I have spent the last 15 years trying to change the way people with serious mental illness are treated. More often then not people are punished for their illness then given access to optimal treatment. There is a correct way to approach psychotic spectrum disorders and it is with Clozapine, Engagement, and Community. That less than 2% of all patients with psychosis are prescribed the safest and most effective treatment is the single biggest failure of mainstream psychiatry to provide adequate treatment. The USA ranks dead list in the civilized world. That said, without engagement therapy cannot even be entertained. Since approximately half of all patients have the organic brain condition called Anosognosia (unawareness of the illness) without effective assisted outpatient therapy (court mandated treatment) we cannot engage. Finally all of these patients need support so we need to invest in getting rid of the IMD exception, limits on care, and provide wrap around services with good supported housing. At present my fellow board member SAA has shown the cost of not caring to be in the ballpark of 500 billion dollars a year. We know that if we can use clozapine we will save approximately twenty five to fifty thousand dollars a year per each individual treated. This was demonstrated by a recent VA study and the NICE study out of England. On a personal level I know meaningful recovery is not only possible but with an optimal clozapine regimen the norm. Both my wife and I have started a new field which we have titled psychiatric internal medicine. Not only is my son Daniel Laitman an example of the success of our approach we now have a client base of over two hundred clozapine patients that are on the whole doing similarly well. The last data we presented showed a seventy five percent meaningful recovery rate. I refer you to our website: Teamdanielrunningforrecovery.org and our book: Meaningful Recovery From Schizophrenia and Serious Mental Illness with Clozapine. Thank you and I always available to talk.

Response 70:

Dear Chairman Wyden,

Hello and thank you so much for listening, for working to make a difference in the lives of our loved ones with severe mental illness. I can't begin to count the number of times we have been told that unless our loved one is a danger to himself or others which is immediately apparent to law enforcement that no treatment can be available to him. This, when we, his family who love him more than anyone else can, see the signs of imminent harm and danger long before the illness compels him to act upon them. We beg you to allow family members to have a voice, to remove the barriers to treatment that so often result in our loved ones ending up in tragic situations, and are arrested, jailed, and all too often, imprisoned without medical intervention simply due to behaviors which are the direct result of a medical brain illness. No one wants to return to the days when a family member could be inhumanely hospitalized for years, just on a family's say-so. However, we have gone too far in the other direction, when those who care the most are unable to obtain humane medical treatment for what is not our loved ones' fault, but a medical, biological brain disease which deserves compassionate, long term treatment in order for our loved ones to sustain a stable, productive, safe and healthy life. Please increase the number of hospital beds, repeal the IMD exclusion, and expand assisted outpatient treatment so that those who are eligible can stay in AOT long term without being ousted due to lack of funding. Long term, not temporary, housing is needed, with a full spectrum of care, from psychiatric to case management, to counseling, to positive, productive opportunities for engaging activities and if possible, employment. Our loved ones have been neglected for far too long. Again, thank you for acknowledging and addressing these crucially needed changes, and for considering other recommendations from the Treatment Advocacy Center, for the lives and health of our severely mentally ill loved ones.

Response 71:

Dear Chairman Wyden,

Dear Senator Young and Chairman Wyden,

I have a family member with Schizoaffective Disorder of the bi-polar type. He has had 22 hospitalizations primarily because he lacks awareness of his condition. While he speaks of having a mental health condition and speaks of his particular diagnosis, he does not always make the connection between his symptoms, triggers, thoughts, his medication and treatment.

He has recently been successful because he was under a civil commitment and felt compelled to follow his treatment plan. As a result, he is reengaged in family, church, and community meetings.

It is a miracle that he has not been in jail or homeless, but with education and family support, we have been able to provide some safety measures.

There is a great need for Indiana to fully fund ACT teams. It is my understanding that the move to block grant funding of the Reagan era resulted in lesser support for the severely mentally ill. Currently, there is unnecessary competition between those that need substance use treatment and those that need treatment and support for chronic conditions of a SMI nature. The sum of money available remains relatively the same. SUD and SMI treatment providers compete for relatively the same pot of money from year to year. With the opioid epidemic, SUD programs have been funded more as of late.

Housing is also a very important issue. SO many of the homeless in our community lack appropriate housing options.

I appeal to you to fund not only systems of care that honor each person's right to self-determination and to engage in his or her recovery plan, but also remedies that recognize that many with Severe Mental Illness lack awareness, like my son, cannot self-initiate. Fully funded ACT teams, AOT and civil commitment, housing first initiatives, and more inpatient stabilization units are desperately needed.

Thank you for this opportunity to provide input.

Response 72:

Dear Chairman Wyden,

As a leader in a peer-run NAMI affiliate, I can wholeheartedly support every recommendation of the Treatment Advocacy Center. In my own family, if all first responders had access to specific training regarding the serious mental illnesses, the seriousness of my brother-in-law's depression would have been recognized long before his body showed he was in starvation. He might have responded to an AOT program in the community at the times of our early calls. He needed over 6 months of institutional care by ignoring his mental illness until the physical body was in crisis. No money was saved.

Response 73:

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Response 74:

Dear Chairman Wyden,

Its a never ending cycle. There is absolutely no where to turn. The only way police will help us is if my family member hurts someone because by her making threats to the police its still nit good enough for them to help us, and if someone is harmed the only thing they will do is send her to prison which has caused mental illness to become much graver.

Response 75:

Dear Chairman Wyden,

I am the parent of a 34 yr old son with schizoaffective mental illness. It was extremely difficult to get the right services for his mental illness. It should not require retaining attorneys and advocates to get care for people with serious mental illness. Society must prioritize those individuals with serious mental illness over general mental illness. They are the most vulnerable population and require the most support. It is unconscionable that we permit this population to end up in jails and prisons or homeless dying 25 years earlier than the general population. Please allocate the funds so people with serious mental illness can live lives of dignity.

Response 76:

Dear Chairman Wyden,

As a mother of a 39 year old son with schizophrenia, I can say it’s been 20years of no hospital beds, no psychiatrists to administer injectable, no apartment for him. Add to that the suffering of the disease and please explain why my son faces discrimination simply because he has a brain disease. I’ve done my part to keep him safe. PleAse Congress do yours.

Response 77:

Dear Chairman Wyden,

To all concerned, The recommendations are good and needed. We really need to get our SMI when they are first diagnosed into long term treatment and stop waiting for them to do a crime that warrants a arrest to go to jail.
We also need to amend the HIPPA so active Family Members/ Caregivers of the SMI are not denied to participate in all treatment .
I am the Mom of an now adult son who struggles daily with SMI. The County of San Luis Obispo has not helped my son since he has been an adult. The county puts him in Drug and Alcohol Programs providing 0 SMI treatment. When he has an episode we have to wait for him to do a crime . This can take years while he is homeless and unable to help himself with dignity. Once he does a crime , gets arrested and acts out in his solitary cell he now has a felony and gets charged , waits long months untreated for a court order to be compensated. Twice this took place and he was finally court ordered to a state hospital . Prior to this he was arrested twice for misdemeanor's and court ordered Behavioral Drug and Alcohol Treatment. His resent 5th arrest my son was placed in the same jail already diagnosed and treated for his Autistic marker, Bi-Polar and schizophrenia. Once again locked up without treatment. Then my son was hand-picked to be used as an experiment for the SLO County jails new JBTC program . They did this without reviewing his aggressive actions becoming more frequent with each break-down. JBTC offers only compensation and 0 treatment for SMI. My son was then court ordered to participate in the new Diversion Treatment. This program offers no SMI help and is again based on Drug and Alcohol.
As I share this with you my son has just been expelled from the Diversion Program, living in our SLO Prado 40 Homeless Shelter and running free without the needed help he should have for his SMI and anger issues.
We have a Family Support Group where Family Members / Caregivers get together once a week to tell our stories over and over.
Our Loved One's have their programs to go too.
Where is the support to bring the Loved one and their real support, US the Family member/ Caregiver. Why isn't there a mediator to help us stay a team at all times?
Forever and ever living in hope

Response 78:

Dear Chairman Wyden,

It is a nightmare trying to help our loved ones who suffer from mental illness. If they do not give us an ROI (release of information) it is impossible to help them and give information to their case managers and doctors. I have 2 daughters who became severely mentally ill in high school. I have been dealing with this for over 20 years! I finally had to obtain Legal Guardianship for both daughters, which cost me $20,000 going through a Mental Health Attorney. Yes $20,000! Who can do that?! It's ridiculous! Even then, if you want them hospitalized, the normal answer given is "if they do not present, and are not "a danger to themselves and others" then we can't! That happened one day before my daughter slit her own throat! The stem is flawed and stinks! it is a constant witnessing your children dying over and over again, everyday of the year. More funding is also needed to find a cure. Please do something positive!

Response 79:

Dear Chairman Wyden,

It took my niece jumping out a 3rd floor window before she received the treatment she needed in the form of 2 years in a long-term state hospital followed by 2 years in a residential group home. Prior to this, she had 7 serious suicide attempts and was only given short-term hospital stays. When the pandemic hit, I found an apartment for her because the group home was not doing enough to keep her safe from getting covid. Her outpatient services are ongoing.

She has been seriously mentally ill since she graduated college. In the 20 years since, she has been hospitalized for acute episodes 15 times. She needed a continuum of care in order to achieve stability.

She is on SSDI, Medicare, and MassHealth. All these benefits have been advocated for and received after much angst and steady pressure from me, her primary caregiver.

Repeal the Medicaid Institution for Mental Disease (IMD) exclusion Repeal the Medicare-190 day lifetime limit Expand federal funding for assisted outpatient treatment (AOT) Establish a national database of psychiatric beds in the U.S.
Request a Government Accountability Office (GAO) report on the extent of psychiatric boarding in emergency departments in the U.S.
Require the National Institutes of Mental Health (NIMH) to establish transparent and peer-reviewed standards for estimating prevalence rates for schizophrenia in the U.S.
Mandate periodic NIMH prevalence studies of schizophrenia, bipolar disorder, and other severe mental illnesses at regular intervals, and explicitly require that prevalence rates be accurate and comport with peer-review protocols Fund programs that are tailored to community resources and divert people with SMI away from criminal justice involvement to the greatest extent possible Include emergency responders with knowledge and experience with SMI— including but not limited to schizophrenia, bipolar disorder, major depression, and other psychotic disorders—in both the planning and implementation of any emergency response models Enforce the bipartisan language in the 21st Century Cures Act that requires the Department of Justice and others to

collect and regularly report data involving law enforcement encounters and mental illness Include racial and cultural demographic information in any data collected to inform future funding and policy decisions related to the treatment of mental illness, as well as reform efforts to prevent and reverse criminalization of SMI Make permanent all telehealth coverage for Medicare recipients that were expanded under Section 1135 authority during the COVID-19 public health emergency2.

Response 80:

This is Patsy Koning regarding information for the finance committee, et al. I had trouble responding through the "request for action" email because I am having many computer problems. In fact I had to write this message for the Finance Committee three times!. Please forward to the appropriate TAC staff. Hope it's what you want

People with SMI face such adversity. Typically there is little understanding by others which truly affects both work and home life for those with SMI. People with mental illness also face higher expenses but often receive less “income” than most people.

I worked for many years before I reached the point where work was not possible. My employer had disability insurance which covered me for two years. At that point I was terminated from the policy because of my diagnoses. Yet a co-worker with a heart condition was covered for life.

Fortunately I was was eligible for SSI. Unfortunately the benefit was less than I received previously, a lot less.

Psychiatric meds are very expensive, so I bought medications from Canada. I was also lucky to find providers who, from time to time, would see me for nothing.   Although MH services are required to be offered by many insurance plans now, don’t be misled about this; many people do not receive clinical, social or pharmacologicaly services. This lack of treatment impacts entire communities, not only the patients. Even I Medicaid, that has generous benefits, it’s difficult to find providers who will accept the very low payments.

Response 81:

Dear Chairman Wyden,

As I age, it is my greatest fear that my son will no longer have access to psychiatric inpatient hospitalization under his Medicare coverage. He had already used his lifetime limit by the time he was 30 years old. If he is unable to continue his meds for any reason (as he ages, lab work out of range, etc.) and he decompensates...what options will be available to him? Being hospitalized several years ago stabilized him. Saved his life! Why doesn't someone with Serious Mental Illness deserve the same benefits as someone fighting cancer, or dealing with a bad heart? We MUST decide that people with Serious Mental Illness should not be put out on the street to fend for themselves where they usually face a tragic demise. Thank for your help in repealing the 190 day lifetime limit. I hasten to add that jail is not a substitute for inpatient psychiatric care.

Response 82:

Dear Chairman Wyden,

I have a son who is 25 yrs old and has been on the streets for 4 1/2 years. It took me until he was on the streets to finally realize that he was truly ill, not just an irate, "crazy" substance abuser. I didn't truly notice the changes in him until he became an adult and by then, I had no ability, or right, to help my very sick son. That is the problem for the majority of us family members. Our hands are tied, and there is nothing we can do to help these poor people who are so very, very ill. And as we all know, they think they are just fine. After my son became an adult, he began acting very strange and would act out to where my youngest son became afraid of him and we couldn't have him live in our house anymore. I tried over and over again to get him to see a psychologist, therapist, doctor, but he refused. I thought he was just acting out, and by the time I kicked him out of the house because of his behavior, I thought for sure he would change his tune and ask to come back, seeking help. However, that has not happened. I finally realized that he wasn't just a depressed individual, he was seriously mentally ill, but I don't really know how I could have done things differently. It greatly saddens me that the only "help" our ill ones have is the judicial system. WHY is this the preferred method?! I can't understand why people with cancer, Alzheimer's, Parkinson's, etc, get preferential treatment and understanding. Over and over again there are ads talking about Mental Health. Not that Mental Health isn't important, and SO many people in society suffer from it, but it's become a norm and we "feel" for these people. Why Mental Health is important, but not Mental Illness? AND it is NOT the same thing, though most people really don't see the difference. Why do we sweep Mental Illness under the rug and pretend it doesn't exist? Why are sick people stuck in jail or prison, because their minds aren't well. My son has been to jail many times, but he's not deemed sick enough because he hasn't committed a felony. So into jail he goes, then he's out a few days later, back on the street. It's a vicious circle. WHY do we spend SO MUCH MONEY in regards to this? For example: my son gets arrested for possession. He goes to court and is given an attorney. Comes back to court for his arraignment. And then back to court for the verdict. This procedure can go on for months. He is always found guilty. Goes to jail for 3-5 days, and is out again. WHY DO WE DO THIS CRAZY DANCE AND SPEND THIS KIND OF MONEY IN THE JUDICIAL SYSTEM RATHER THAN GET THEM THE HELP THEY NEED IN A HOSPITAL? I used to live in Australia. When the authorities find that a mentally ill person has committed a crime, they put them in the HOSPITAL, not jail. What has this country come to, that we feel our sick, fellow citizen deserves jail rather than a hospital? We need more psychiatric hospitals and qualified staff to help our loved ones. This has been a problem for decades and WE NEED CHANGES NOW!!

Response 83:

Dear Chairman Wyden,

I'm a mother of a 36 year old son who has schizophrenia, he became ill at the age of 22 a full time college student so close to achieving his dream of receiving his B.A degree. Only to struck with the worst, debilitating disease schizophrenia for which there is no cure. My son was so heavily medicated he developed a movement disorder Tardive Dyskinesia this has left him unable to care for himself. I didn't know anything about mental illness it was one of the most difficult times for my family. I tried several times to have him admitted through Kaiser Permanente emergency unit, waiting over 8 hours at times only to be told he wasn't a danger to self or others, I can count the number of times I left crying wondering why no one wanted to help me help my son? While hospitalized at Canyon Ridge Behavioral Center, he was attacked and sent to the emergency room I nearly died that day, there sat my son on the bed with his lips busted and blood running out of his mouth, someone broke his front teeth. There were no answers given all I was told is he had a seizure my son doesn't suffer from seizures he's 6 feet tall. While being hospitalized at Kaiser Permanente Los Angeles Behavioral Ward, the treating psychiatrist refused to continue to care for my son being the County of San Bernardino Authority refused to grant conservatorship. While at this center his white blood cell count dropped and he developed rhabdomyolysis he developed a subcutaneous cysts which required surgery. I've had to deal with not being able to speak with his doctor on his behalf unless he ok's the call. The duration of treatment while hospitalized needs to change he would return home in a worse state of mind than he was admitted, only to cause him more anxiety and depression. The majority of visits to the E.R were the worst times I've had to endure the employees would mock my son, and refuse him needed treatment being that " he wasn't dying". Discrimination exists today and I've witness my son being treated as he didn't matter, I'm thankful I can be his voice I'm his advocate but think of the many unheard voices who have no one? I implore you to please make changes so badly needed for our broken mental health issues, provide more psychiatric beds.Repeal the 190 day lifetime limit,. Include emergency responders with knowledge and experience with SMI.

Response 84:

Dear Chairman Wyden,
Please end the IMD exclusion and the lifetime limit on mental health care.

Response 85:

Dear Chairman Wyden,
Social and policy response to mental health is inadequate, barbaric, and counterproductive. Addressing cultural despair and pain of suffering, mistreatment, and stigma is appalling for civil society.

Response 86:

Dear Chairman Wyden,

Arizona's behavioral health system (BH) has failed us so many times it's difficult for me to pick out a particular one that's more egregious than another. When our son first became symptomatic with his disease, which turned out to be schizoaffective disorder, we had to fight the BH system. At first they denied him being seriously mental ill at all and, after two appeals, we were scheduled to go before an administrative judge when, for some unknown reason, somebody canceled the court hearing and he was finally determined to be SMI. Our son was assigned to a Choices ACT team and our experience with that ACT team was even worse, if anything, than before he was determined to be SMI. They did not provide the services he was entitled to, and the head of the ACT team (clinical director) was extremely unsympathetic, uncooperative, and frankly incompetent. Our son was evidently a “difficult“ patient and the ACT’s team solution was to decide, all of a sudden, that he was not sick and no longer seriously mentally ill. This assessment occurred during regular staffing when they wanted five minutes alone with him before the beginning of the meeting. They then told us that they were canceling the meeting and that they had “determined” that he no longer was seriously mentally ill. They tried to refuse him services. This, of course, after years and years of him being denied services through our group health insurance on the private side due to non-compliance with parity law. This decision, by his “supportive” ACT team was eventually overturned after review by another psychiatrist.

Response 87:

Dear Chairman Wyden,

In 1970 my younger sister became very ill with schizophrenia. She was in hospital 3 months where a treatment plan was initiated. She returned home to live with our parents continuing the medical stabilization begun in hospital along with ongoing eval by dr and much emotional support and education to help her understand what had happened to her to elicit her cooperation in recovering her life. This took about 2 years. Today she is 63 years old, has a family of her own follows the medical and supportive treatments. She has a shirt that she wears which says all it takes is all I’ve got” . She is grateful that she received the care and treatment she did. In her case there were no barriers. I recently retired as psychiatric nurse at an outpatient clinic in downtown St Louis. We saw many homeless persons very mentally ill released from a 5 day stay in hospital discharged home(to the street) many disenfranchised from their family, still very ill, having little recognition of how ill they are and what it will take to recover. I urgently recommend the first 3 recommendations ie: repeal imd exclusion, repeal Medicare 190 day lifetime limit and expand the federal funding of assisted outpatient treatment (AOT).

Response 88:

Dear Chairman Wyden,

My unmedicated seriously mentally ill son accidentally killed a child psychiatrist in Utah in 2020. Throughout 2020, there were many people who "touched" my son's care, myself included. At one involuntary suicidal admission for playing russian roulette over the phone, the hospital released him back to his belongings within 6 days, where they did not check to see if he still had a gun. Two month's later he shot off a gun in the park. Then he got Covid. Off his meds and suicidal, then onto the streets, then a road rage incident causing the tragic crash and death of Dr. Arthur Miller. I ask that HIPPA laws be changed so families can be made aware of the care or lack of care taking place for our adult children suffering from serious mental illness. I know what can help my son. I know when he should be involuntarily committed. A death could have been prevented. Please listen to us parents! We know! Change HIPPA laws for the seriously mentally ill who often suffer from anosognosia.

Response 89:

Dear Chairman Wyden,

1.Expand federal funding for assisted outpatient treatment (AOT) 2.Establish a national database of psychiatric beds in the U.S.
3.Fund programs that are tailored to community resources and divert people with SMI away from criminal justice involvement to the greatest extent possible

In May of 2017 my son Andrew died in SLO County jail after being strapped naked to what was commonly called "the devil chair" for two days. When he was dumped onto the cold cement floor, after 46 tortuous hours, he crawled several feet collapsed and died of a massive coronary embolism. He was 37. And although he suffered from Schizophrenia, he was valued; he was an amazing son, brother, and friend.

Andrew needed treatment for his disease but our County offered very little for anyone suffering with SMI. We need expanded federal funding.
There was no place we could find help for Andrew, though we tried. The two very expensive 'dual diagnosis' centers we tried sent him home without reimbursement as soon as he showed signs of psychosis. There simply were not any mentally ill hospital beds available to treat him. We need to establish a national database of psychiatric beds in the US.
The last place Andrew needed to be was in jail. He was terrified of the police and acted out when he saw them, believing he was in danger. This created the very problem he feared. We must begin to fund programs that are tailored to community resources and divert people SMI away from criminal justice involvement to the greatest extent possible.
Andrew had a brain disease, but it never took away his humanity. It didn't take away his love for life and family, or our love for him. But because of lack of resources and public support and understanding, it did cost him his life. We must find a better way.

Response 90:

Dear Chairman Wyden,

My brother suffers from mental illness and last year he went missing. We did everything possible to find him and we did. After this horrific experience we tried to have him under LPS Conservatorship but unfortunately we never obtained it. After finding my brother the Dr. only hospitalized him for three days. Our family was in complete shock and disbelief that the Dr. had discharged him so quickly. He was not stable and in three it was impossible that he would be become stable. He went missing again because he was so aggressive he could not stay with us and we did not have SSI benefits which pay for housing and he went missing again. It would several more times where we would find him and we would not be able to obtain the LPS Conservatorship.
Now he is stable and living with us. Most families do not have the same experience as we do. They are still living through the horrible experience of not knowing if there family member will be found alive.
Please help our families , as we are in a crisis.

Response 91:

Dear Chairman Wyden,

As a parent of an adult son with SMI, Bipolar1, it took 10 years of "treat and street" before he was at last admitted to a long term stay at the Montana State Hospital. (He has now been well for over three years, working and staying healthy by managing his illness.) Anecdotal; The Bozeman Deaconess Hospital has NO psych ward. They actually took my son, who was clearly psychotic at the time, and dropped him out on the streets at 2 am. Never called me. I found him wandering side streets days later in a psychotic fog. Our oldest son, Dr. Abraham Bombeck, a psychiatrist, says Bipolar and Schizophrenia are now being considered medical diagnoses, not psychiatric. Certainly, SMI should receive the same financial support as any other medical condition. My wife and I, and our adult children, strongly support all the recommendations of the TAC.

Response 92:

Dear Chairman Wyden,

I have a 54 page report written on how hard it was to get care. It took over 5 years!
I will be happy to share the report I wrote.
My daughter is 17 now and hasn’t been able to attend school, etc. because of a broken mental health system.

Response 93:

Dear Chairman Wyden,

My loved one has severe bipolar disorder with psychotic features. When he was at his sickest (in the state of Iowa) no beds were available, so he was "boarded" in the local ER and shot full of Haldol which can cause a decrease in brain volume. It took 24 hours for a bed to become available, and he was transported 70 miles from home in the back of a police car while unable to speak. Having a psychotic episode is like having a stroke and can do brain damage. It is a medical emergency. The hospital ER staff would not tell me or any other family members where they took my loved one. Once my loved one was well enough to speak, he immediately called me terrified and wanting to see me. The government needs to immediately end the IMD Exclusion so more hospital beds can be put in place for appropriate treatment of the sickest people with severe mental illness. The IMD Exclusion is very discriminatory against those with severe mental illness. Also, there needs to be a national database of psychiatric beds established. Furthermore, mandates need to be given to the NIMH to continue to engage in studies of medications specifically for people with bipolar, schizophrenia, and other severe mental illness. Emergency responders need to be available who have knowledge and experience with persons who have severe mental illness. PLEASE LISTEN and ACT. I support all recommendations by the Treatment Advocacy Center, as the family member of a close loved with who suffers from a severe form of bipolar disease. Thank you!

Response 94:

Dear Chairman Wyden,

To Whom it May Concern:

These stories run parallel to mine, it's truly heart-wrenching as well as comforting to read the likeness of history and experience with others who have sons/daughters/family with SMI that spend years without proper individual, monitored, safe housing options, even with case management teams' efforts.

I've lived in AZ since John was 4, he attended Kindergarten through High School with teachers saying "there seems to be a processing problem" or "perhaps some extra help" from Sylvan Learning Centers, tutors, Kumon math, extra credit assignments, something in the line of "special learning opportunities" was suggested. Grades suffered, despite the cooperation his father and I showed by jumping on every one of the "ideas" we received... John showed apparent skills in Math for instance, by solving problems mentally and giving the correct answers, but received "D's" and "F's" for using a pen not a pencil and not being willing to show his work (that was in his head not on paper). Meanwhile student/teacher ratios were 30-1 ...individuals with unique learning needs fell by the wayside, and my son was told he could not march in HS graduation ceremonies with friends he went to classes with since kindergarten, because he was shy three credits. I had to beg for grace and suggest they offer him a way to achieve that rite of passage through special assignments! My taxes were paying them to take care of a solution which I finally came up with, and John wrote three brilliant essays one teacher told me was either plagiarized deserving an "F" grade or so intelligent he had to give an "A+"! He gave him a justified A+!

These are the common foundational experiences of a parent having a child that was a square peg being forced into a round hole that eventually began to desire to level their playing field through heavy metal music, smoking cigarettes or trying marijuana and other stimulants to feel noticed and a distinction from being "a lost cause" or "dumb" or "weird".

Mental illness observations often follow in and about early adulthood and my son's case was determined to be bi-polar mania II and schizoaffective disorder and the darkened behaviors manifested. Law enforcement confrontations escalated, misdemeanor charges began, and penalties mounted up with legal fees, medical fees and emotional distress on the families.

Many "help" groups and organizations, churches, Etc serve their communities to a greater or lesser degree depending on funding and participation but the life style of families seeking help 24/7 for their loved ones battling serious mental health is exhausting, often destroying marriages, health and finances in the sincere attempts.

In all humility true HELP looks to me like safe, secure, expertly - crafted and monitored "personal interest housing" in a "community" setting (like a village) complete with amenities and necessities and an encouraging supportive administrative team of professionals trained as case/village managers...near mental health and medical facilities ...to be servicing and improving the lives of the most ignored, disparaged, downtrodden people group, the mentally ill populations who need a "master-planned environment" of support, safety, help/education and respect.

Anyone with a chronically mentally ill/SMI person in their lives hears their loved one's cries for "a place of my own, a modicum of privacy, the same bed and bathroom and perhaps a pet to care about " ...all desires for personal space and good housing and recognition.

I hope and support any effort to make this dream of their's come true. Could it be possible?

Response 95:

Dear Chairman Wyden,

In Philadelphia there are so few acute in-patient beds and extended in-patient beds for people with mental illness that families see their loved ones admitted and discharged in a few days with no discharge plan. Many people with MI are sent to shelters or end up on the street or in jail. We desperately need: more psychiatric beds (acute and long term); affordable supervised housing; more out-patient programs; more mental health professionals and para professionals.

Response 96:

Dear Chairman Wyden,

My 31 yr old son, who has suffered from mental illness all his life has been in psychiatric hospitals at least 8 times. He has been in jail and he spent 2 and a half years in state prison. Why? Because he suffers from mental illness. No hospital has kept him more than 2 weeks; most often 10 days. I hired a mental healrh advocate attorney to go before a judge to advocate for court appt treatment. All the judge did was throw my son in prison and throw away the key. My son was released from state prison in April 2021 a broken, terrified young man. SOMETHING HAS TO BE DONE!

Response 97:

Dear Chairman Wyden,
I am a mother of a 25 year old son with SMI, schizoaffective disorder, Borderline Personality Disorder, and intellectual Disability. I am an RN since 1984 and working full time in a local hospital. We are residents of Charleston S.C. He was referred to Babynet/ DHEC at age 2 for developmental delays at age 3 was placed in public school system Childfind and then in RESOURCE program at school for learning delays. He was a happy active child until at age 11 in 5 th grade he realized he was different than the other children. He stated, " Mom , I'm retarded and I want to hang myself." I worked through many barriers in the public school system to get his educational needs met. It was not until I had him evaluated by the outreach program at Trident Academy to get a better evaluation of his learning disabilities. Trident Academy is a private school that cost $25,000/ year. Unfortunately I could not afford to send him there. He was evaluated and found his brain processing in the 4 th percentile and severe reading disability. I petitioned the public school system to provide EVIDENCE BASED READING PROGRAM

for him and finally they hired one. Realize he had been in EARLY INTERVENTION SINCE AGE 2! Now at age 11 he is finally getting the EVIDENCE BASED READING PROGRAM that he should have gotten much earlier !! I got involved with a PARENT ADVOCATE to help meet his needs, it was still a struggle all through school! He struggled through school until finally at age 17 he dropped out. At age 13 he started developing severe anxiety and by age 15 he had his first psychotic episode. He was admitted to MUSC IOP in Charleston SC to the Psych unit. This was the beginning of the struggle of meeting his mental health needs. This is an Acute Care Psychiatric unit. This was the beginning of multiple admissions. In 2014 I was introduced to NAMI (National Alliance on Mental Illness) and I attended the 6 week Family to Family program. His father left in 2014 and was not able to cope with our family situation. My health insurance through the hospital only covered acute care and was not enough to take care of his ongoing mental healthcare needs. I tried to get him on Katie Becket MEDICAID (not sure if spelling is correct) but at the time his father and I apparently could not qualify financially. We made less than $100,000/ year together. At the recommendation of a Social Worker I sent my son to Asheville NC to a camp for teens (he was age 17) the cost $30000! I took it from my home equity line of credit. At 11 days into this camp we got a call that my son was so severely mentally ill that they could not let him continue. We were out of options for long term care for him. They sent him to their sister company out West and my son got an extensive psych eval. With a firm diagnosis and they noted he was not on the correct meds. I had to pay $5000 each time he was transported by a private organization so that he was safely transported. This was beginning to financially burden us to the max! This program out west was an intensive 1:5 ratio of mental healthcare provider to patient and he got the best care and evaluation there…. Private pay. Sadly This program no longer exists due to it being cost prohibitive. My son was almost 18 and the recommendation was that he needed Long Term Care in a facility. They recommended a great private one at a cost of $100,000/year. I contacted a Social Worker at MUSC and Charleston Mental Health for direction. He had to he out of my home for 30 days to qualify for Medicaid otherwise I would have to come up with money out of pocket to find placement for his care. We could not sustain this financially. He was transported by Sheriff to the State Adolescent Psych Hospital in Columbia SC for 30 days. This was all recommended from the Social Workers I worked with. They truly cared about our son and tried the best they could to assist in getting my sons needs met. He was finally APPROVED for Medicaid and transported to Three Rivers Adolescent Facility in Columbia SC. They only kept him for 3 months then he was sent back home to me, his Mom/Legal Guardian(which cost me $5000 to obtain through the court) there is so much more detail to our story. Now he was back to me and in and out of Adult Psych at MUSC at age 18. He was at a palmetto behavioral psych inpatient a few times as well. Finally he was admitted to Palmetto Behavioral Psych for 16 months. This was a horrible experience. Young people ages 9 to 21 with multiple diagnoses ranging from rapist out or DJJ system to those with severe Autism. He was finally placed on Clozaril which helped him the most. He was tried on many medications over the years. He developed a Pilonidal Cyst Abcess and needed surgery. Palmetto behavioral gave me 3 days notice that he could not return because they could not care for his wound. He was soon to turn age 21 and then he could no longer qualify to stay due to his age. He was sent back home to me. He is still a client at Charleston Mental Health. He has been to MUSC PSYCH ED more times than I can count. He was sent to Antonio Staples Group Home, Shalom Recovery House, and Cabading Group Home over the past few years. He ran away each time and called 911 for help and was taken back to MUSC PSYCH ED. I have contacted every STATE agency possible for help. I have spoken with the SC

STARE ATTORNEY GENERAL, SC STATE OMBUDSMAN, STATE MENTAL HEALTH FAMILY PATIENT advocate…. All who state they are aware how broken the Mental Health System is…I am struggling to help my son get placed in a safe appropriate group home and it is devastating the conditions these group homes are places that are not safe and less helpful than the Homeless Shelter. We are in desperate need of housing and programs to help our loved ones to live safe and healthy lives. This is only a tiny glimpse of what we have been through to this point! Please help!!!

Response 98:

Dear Chairman Wyden,
Monitoring New Hampshire hospital revolving door policy on holding people against their will for fabrication of documents to support long term dependency on social security.
10 year mental health plan not working for clients but staff paychecks not conducive to helping overcome mental health issues by encouraging empowering independent lifestyle.
Monitoring Tri county cap guardianship/ office of public guardian for misuse of clients social security benefits for profit.
My now 33 year old daughter Nicole soucy currently receiving NFI transitional housing programs where administrative support staff going on opinions hearsay based labeling nothing credible.

Response 99:

Dear Chairman Wyden,
Having a family member have a mental health crisis in the United States is a nightmare. Our son started with mental illness at the age of 21. When we called police for help, our son was always arrested and put in jail. There he got no help or treatment. Once when he was taken to the emergency room, we were told there was no place to send him. They asked if we could take him home and stay up all night on suicide watch. And if you finally get them into some kind of treatment, the HIPPA law denies you any kind of access to their treatment or diagnosis. We need to repeal the Medicare-190 day lifetime limit. Mental illness can last a lifetime. We need emergency responders with knowledge of mental illness. Not just take them down and put them in jail. We need to expand federal funding for assisted outpatient treatment. We need to fund programs to divert people away from criminal justice. There needs to be a national database of psychiatric beds in the US. We need to repeal the Medicaid institution for mental disease exclusion, Mental illness is here to stay unfortunately. Families across this nation are suffering. It is almost impossible to get help for a loved one. Especially if the mentally ill person feels there is nothing wrong with them. I have lived this for 15 years and it doesn't go away. Please help the families who are suffering!

Response 100:

Dear Chairman Wyden,

I am the mother of a 46 year old son who has suffered from a seriously psychotic disorder for over 25 years. In San Francisco Ca his Kaiser HMO kicked him out of psychiatric care in 2003 telling me that he would get better care in the county. Since then he has been hospitalized over 100 times on short term stays and has three times been placed on temporary conservatorships. He has used up all of his 190 inpatient days paid for by medicare. San Francisco's department of health has allowed the closure of over 100 acute inpatient beds for psychiatry at the county s hospital and has allowed non profits such as Sutter Health to expand without requiring any inpatient psychiatric beds. The SF jail continues to be the provider of choice for this population while our department of health tells parents such as myself to let our psychotic loved ones hit bottom on the streets so that they qualify for California's ridiculous definition of grave disability.

The IMD exclusion must be repealed. There should be federal funding for AOT programs and federal standards for how those programs are administered. In Ca each county makes up its own rules. There should be full parity for these brain diseases. Today people on Medicaid and Medicare do not get parity for mental illness and this is an outrage. There must be full accountability for outcomes when states are given federal funds for programs. HIPPA laws need to be changed so that families can at least find out if their loved ones are in an ER or the hospital.

Response 101:

Dear Chairman Wyden,

As the mother of a son with schizophrenia, we have had so many harrowing and counter-productive experiences with the mental healthcare system that I actually wrote a memoir about it to vent my frustration and blow a whistle on the horrible treatment that people like my son with SMI endure on a daily basis, in masse, throughout our country.
The Treatment Advocacy Center has outlined a series of solutions for your committee to review and I whole-heartedly agree, with many of those issues having affected our family directly.
The IMD Exclusion must be repealed. This is outright discrimination against the most vulnerable population. Mentally Ill Lives Matter!
My son was on the streets of L.A. and there was one glimmer of hope when an AOT team began to work with him, but there was a two month waiting list to get started. People actually die before they get the help they need.
Schizophrenia is a neurological brain disease and it needs to be studied, researched and funded like any other physical disease. More funding also needs to go directly to programs which will assist those who are so disabled that they don't think they need help and there needs to be more robust outreach to them. Preventative care will cost less than incarceration or the toll on cities and other citizens trying to provide emergency care after the fact.
One solution not expressly mentioned in the list is the desperate need for authentic therapeutic long term housing. If people with serious mental illness had an inviting residential program to live at, where they can be safe and receive high quality care, frankly there wouldn't even be such a need for more hospital beds, diversion programs, and emergency care.
In Southern California, the John Henry Foundation serves as an excellent role model for long term therapeutic housing. This is a must! To only give people with SMI temporary care or relief is like giving anyone else with a life long illness only a few weeks or one year of care and expecting them to be stable, when that is impossible.
If any committee members would like a free copy of my book, "Noah's Schizophrenia: A Mother's Search for Truth," I am happy to send copies to anyone interested.

Response 102:

Dear Chairman Wyden,
Presently, I am administrator for FB, group Parents and Advocates Of Families of Seriously Mentally Ill. Our adopted son who had auditory hallucinations, and is autistic has been in prison since he was 17. Charged with trespassing in a paranoid delusion. We need institutions, treatment and housing, for the mentally ill. We can do better then homelessness or Prison. We help everyone else, but our own Mentally ill. Please help us!

Response 103:

Dear Chairman Wyden,

The mentally challenged & homeless need more help, NOT LESS. Many of the homeless are that way because they can't get proper evaluation and have to jump thru hoops to get help and they can't jump thru those hoops without help. We need more mobile units to come to the streets instead of expecting the mentally ill to get on a bed s to go to Santa Ana

Response 104:

Dear Chairman Wyden,
I am a dad of a beautiful young 24 year young man. He was on scholarship with three classes to graduate with a degree in physics and English, when he had his first episode psychosis and was diagnosed with schizophrenia. The HIPPA laws and system have successfully blocked every avenue to Sam's treatment and recovery. Our family is living the nightmare imposed by a flawed, no broken system. Even with our own money and resources, we can not get him into treatment due to his inability to perceive his illness. He is mad, how do you expect him to reach out to treatment without the support and guidance of his family. We need glass and a system that will facilitate appropriate forced treatment. Please help. Our son.

Response 105:

Dear Chairman Wyden,

My 58-year old daughter has been hospitalized close to 50 times in her lifetime, with all of them involuntary admissions. She has truly fallen through the cracks in the mental health care system, and now lives a non-life.
HIPAA has been a huge barrier to family care-givers, such as myself, who is her only support system for the last 40 years, which could only be described as abysmal.
Nobody has ever addressed the problem of "when one gets sick, two need help".
I could go on with a litany of the inadequacy of care for those with a no-fault neurobiological brain disease, who have no voice, and if needed, would be happy to give more detail upon request.
I am a founding member and past President of NAMI Franklin County, Ohio and involved with advocacy at the local and state levels.

Thank you for your attention to a much needed reform for the system of care of our most vulnerable severely mentally citizens.

Response 106:

Dear Chairman Wyden,

Due to COVID lockdown with therapists, my adult son lost his all community supports, in March 2020. Isolated for months, without his weekly therapy, he tried to go off his meds. That resulted in 3 separate hospitalizations, with 12 months inpatient.

The most severe ER boarding encounter was 10 days of restraints because the ER couldn't find a bed, and also because they did not have meds to treat him. The prolonged restraints contributed to increased paranoia and panic. The ER was too busy to handle him, and needed to keep him sedated with Haldol. The months of inpatient that followed was long and costly.

Two of the highest contributory factors :
1) understaffing
2) inappropriate access to effective meds. The only available meds giving were those developed 30 years ago. These meds have high degree of side effects, which is the reason for non compliance.

In this era of scientific progress in therapeutics, not enough focus is on development of effective antipsychotics that patients would WANT to take. Non compliance to meds because of side effects is the leading cause of relapse and long hospitalization.

Response 107:

Dear Chairman Wyden,

Federal funding for Assisted Outpatient Therapy (AOT) needs to be significantly increased to save the lives of people with severe mental illness who end up in jail for minor offenses such as trespassing, sleeping in their car, etc. AOT would be cost effective and cheaper than jail or hospitalization and lives could thrive instead of getting caught in the downward spiral of the criminal justice system.

Response 108:

Dear Chairman Wyden,

Hello,
My name is Nicole Dent. I'm 42 and live in New Orleans with my son Bryan, 25, who currently suffers from Schizoaffective Disorder. He was diagnosed about 4 1/2 years ago and our lives have changed tremendously since. Prior to Bryan's diagnosis, he was a normal kid attending Depaul University in Chicago, IL. It was shortly into his second semester when I realized there

was something seriously wrong with him. I made him come back to NOLA and we've been struggling ever since to get back to "normal".That was a brief synopsis of who we are, now I will describe the issues within our system here in Louisiana as well as other parts of our country.
I want to start by emphasizing the fact that Serious Mental Illness is a disease of the brain. The brain is the central zone of our bodies. If our brain can not properly function, it causes our body to break down. We need the brain for simple movements such as bblinking the eye and so on. I say this to say, why isn't menatl health taken more seriously??? You don't have to be a doctor to understand this simple theory. The brain is our most important organ in our body and witout it we can not live. I just wish that diseases of the brain would be recognized on the serious level that a brain tumor or cancer is.
1. Funding- Why on God's green earth would funding be cut and made difficult to receive for people in need of treatment. It is clear our government has the money as we saw with the free for all during Covid... i.e., PPP loans, and more unemployment than anyone could've ever imagined. Last year, my insurance company paid over 400K in medical bills for my son's treatment. I have no clue what Medicaid paid....he has been involuntarily committed more times than I can count. With proper funding for programs like AOT, this cost could be lessened for myself, the insurance company, and Medicaid/ the State. It could also prevent larger issues like homelessness. My son is fortunate because he has me, but everyone does not have the same fortune. I am writing not just for my son, but for the other countless people who go untreated, become homeless, jailed or even die because they simply didn't get the treatment they needed. I need people to realize SMI is a serious and growing issue all of our communities are facing and we neeed a change NOW! Starting with providing adequete funding to hospitals, mental health organizations, community programs, and etc.

Response 109:

Dear Chairman Wyden,

Alone it is just one person against the world….
United we can move mountains
The Death of Hobo Joe

It's with a heavy heart and a sadness that I did not know existed in a human soul that I would like to share with you the passing of my son, Joseph. He was raised in Oceanside and in his adult years lived in the transient camps around Oceanside Blvd.. He was found Wednesday, October 6, 2021 in some bushes in Oceanside, CA. He was alone in the rain. Still wearing what appeared to be the hospital gown that he was wearing when he was dropped off by staff from the behavior health hospital on that previous Monday afternoon.

His death is a tragedy and could have been prevented if the doctors and social worker had truly listened to me when I begged them to not release him to the streets. I told them he was gonna die. His cause of death is under investigation by the San Diego Coroner.. An autopsy will be performed within the next few days. He just turned 30.

For those of you who do not know my son's story, it's not that much different than thousands and thousands of families out there. Joseph lived in transient camps in San Diego County with severe mental illness. We wanted him to live with us. In fact, we took early retirement to move him and us away from San Diego County 350 miles north to a small town in the foot of the Eastern Sierra mountain range. This area is where I was raised, and where we would take our children on vacations to visit my family. We felt that taking him to the mountains where he loved hiking and fishing, giving him a stress free life in the mountains and “loving him up” would "cure" him. I was delusional on that idea. Bishop did not have the level of care needed to treat his mental illness as well as his chronic medical problems. There is ONE County psychiatrist for the entire Inyo County, and she was trying desperately to retire.

His delusions had him convinced that living up here with us was endangering our lives. He was certain that if he did not leave and “surrender”, " they" would bomb our house, kill us, and put him in a cold dark room to die (not unlike the padded cell in jail where he would spend days at a time in, naked in a straight jacket). There were many nights I had to sleep in the bedroom with my adult son because he was terrified and convinced the SWAT Team had our house surrounded, bombs in hand. You see he was also was developmentally delayed and had an IQ of 70 on a good day.

He was continually being driven home by the Bishop PD because he would walk the two miles to their station and turn himself in.. He lived with us for only several months, and thinking he was saving our lives, he went back to the streets of Oceanside CA., in San Diego County. That was 3 years ago. Since that time his life had been a revolving door of mental hospitals, medical hospitals and jail. He has been hospitalized in behavioral health hospitals at least 9 times this last year. Sometimes against his will, oftentimes he would admit himself. On many occasions I would drive the 5 hour trip to pick him up, get a motel and would try to convince him to come home. He always refused. Stating our house would be bombed if he did.

I'm also angry...that's not even a strong enough word. Joe admitted himself last week to a Behavioral Health Hospital in Rancho Bernardo. That was his “go to” place. He liked the staff and doctors and they seemed to care about him. It was there 2 months ago that the psychiatrist determined he was unable to care for himself and referred him to the County Conservator’s office so his dad and I could gain control of his medical needs and help him obtain the long term help he needed. The conservitor investigator denied the claim because he did not meet the criteria of gravely disabled. In California the bar is set very high to meet the criteria of being gravely disabled. I have yet to know of anyone being successful with that endeavor in California. Accept Britney Spears. Her conservatorship is a slap in the face to those of us whose loved ones truly need help.

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Last week Joey admitted himself because he was feeling suicidal and was psychotic. He would always call to tell me he was trying to get help. He wanted help so badly. On Friday, October 1st the social worker called. She was working on his discharge plan, and assured me that he would not be released to the streets. She was working on getting him reestablished with his care management team and finding him long-term housing, or into a temporary placement at a local Crisis Center. I stressed that he could not be released to the streets. She assured me he would not. Monday morning, October 4, the social worker called and said he was being released and would I pick him up? I asked what happened to the management team and housing? She explained that the care management team had not called her back and no one would accept him at the crisis centers because he had been violent with staff. I instantly asked her why she would ask me to pick him up if he had been violent? I begged her to have him put on as 5150 3-day involuntary hold, (because he was a danger to others) to buy me some time to figure out what to do, and also give me time to make arrangements to drive the 300 miles to pick him up, She said she was heading to a meeting about him and would talk to the doctors. I was clear when I stated to her that under no circumstances should he be released to the streets. I said, " He is gonna die if we cannot get him the help he deserves" . She assured me they would not release him to the streets, and would get back to me later that afternoon.. She did not.

I called the hospital to talk with Joey that Monday night, he was no longer there. Still no call from the social worker. Tuesday morning I called the social worker at the hospital, yet again. She explained that her " team" had given my son a ride to Oceanside and dropped him off at a CVS pharmacy with his prescriptions and a sack lunch. I was in shock, hung up and waited for Joseph's call. He always called.

His body was reported to the sheriff's office the next day, Tuesday night, October 5, 2021, but because of bad weather they could not locate him with drones. The homeless lady who reported him took them to his body Wednesday morning, October 6. He was still wearing what appeared to be his hospital gown and had a baggy of white powder clutched in his hand. He was steps from the homeless camp. The coroner explained that it appeared he got some bad meth laced with fentanyl. Although suicide and foul play have not been ruled out…. What kind of crazy fuck places meth with fentanyl? It is deadly and kills almost instantly.

I'm so angry and devastated I want the system to pay for failing him. I want accountability. I'm so angry it's consumed me. I don't want to be consumed. In.my grief I called a wrongful death attorney and babbled like a banshee.. I told them I needed an attorney with enough balls to take on the "system" and make the "system" accountable for my son's death and the needless deaths of all the other Josephs out there. I want justice, awareness , accountability and the laws changed that bind the hands of families trying to get help to save their loved one's lives . I promised my son his death will not have been in vain. The attorney politely said they will get back to me. I doubt it.

Meanwhile we sit here trying to figure out where we will come up with the money to bring our son home and have a memorial for him. Death is such a money making business. For a fee of $750 he can be cremated. For an extra $250 we can buy 30 minutes of time to see our son's dead body and tell him goodbye . ..That is if he is in viewable condition. After all, he had been left in the elements for over 24 hours and at the coroner for a week. He probably is beginning to smell and not looking too good. For an additional 800 they will make him viewable.

I want justice and accountability so no other family will ever have to receive the call that their mentally ill loved one has been found dead, in the rain, in the bushes , alone and afraid.

Response 110:

Dear Chairman Wyden,

I am the mother of a severely mentally ill adult who has needed hospitalization A number of times. Due to the bed shortage it is a miracle he is still alive. If they will keep him long enough to stabilize him, he does well for periods of time. if they don't he just ends up back in the hospital again. Or he will end up in jail or dead but so far that has not yet happened.

You need to repeal the IMD exclusion. You need to repeal the 190 day rule. It is discriminatory and in the long run shortsighted and costly, in dollars as well as in human misery. If people could get the care they need promptly and stay long enough to get stabilized, you will save money in the long run on hospital costs, crime andjail costs, homelessness costs, et cetera.

Response 111:

Dear Chairman Wyden,

Dear Members of the Senate Finance Committee:

I have five family members wo have suffered from severe mental illness. We have struggled, unable to get hospital beds because of restrictions of the IMD exclusion, because of antiquated laws maintaining that the patient answer to the fact they are a threat to themselves and others (which many patients will not do even if they are a threat or because of anosognosia).

In Virginia at least, as in other states, families with relatives suffering from schizophrenia learn to lie about suicide so that an afflicted family member will be admitted to the hospital. Even then, they are never able to stay long enough for a medical trial and they are often dumped on the street or discharged within a few days, leaving a severe medical problem in the hands of unequipped and overburdened family members who become hopeless and who suffer from severe anxiety, depression and PTD.

I have visited more emergency rooms than I care to remember. In fact, I constantly try to block all memories of the all the incidents. My childhood and adult life have been spent caring for mentally ill family members and it has taken a toll. But my toll is nothing compared to the torture of living with Severe Mental Illness. I can tell you with certainty that the death of a sibling is easier to deal with than the madness of a sibling.

Please accept the recommendations the Treatment Advocacy Center has put before you. Please count the number of schizophrenics in the US so we can know the scope of this problem. And please repeal the IMD exclusion so that patients are not dumped right back onto ailing and aging parents who are totally unequipped to deal with it. Can you imagine if you had a rare cancer, then were hospitalized for two days, then sent home and told that you had to figure it out on your own and that your parents could tend to you and pay for your outpatient treatment?

The situation is so hard to describe and so painful to live through that I find I can barely write about it. I will end this letter now by saying that it is unconscionable that in the world’s greatest democracy, whose benefits we enjoy every day, we continue to deliberately bury our heads in the sand. We have the power to change this situation. We know the cost is extremely high if we do not enact change. The cost to our society is very deep, very expensive, very painful, and very dangerous.

Response 112:

Dear Chairman Wyden,

This is essential for patients with SMI. My adult son is schizoaffective. When he is off his meds in patient care is frequently necessary. Limiting it to 190 days will leave him untreated and on the streets.

Response 113:

Dear Chairman Wyden,

Repeal the Medicaid Institution for Mental Disease (IMD) exclusion Repeal the Medicare-190 day lifetime limit Expand federal funding for assisted outpatient treatment (AOT) Establish a national database of psychiatric beds in the U.S.
Request a Government Accountability Office (GAO) report on the extent of psychiatric boarding in emergency departments in the U.S.
Require the National Institutes of Mental Health (NIMH) to establish transparent and peer-reviewed standards for estimating prevalence rates for schizophrenia in the U.S.
Mandate periodic NIMH prevalence studies of schizophrenia, bipolar disorder, and other severe mental illnesses at regular intervals, and explicitly require that prevalence rates be accurate and comport with peer-review protocols Fund programs that are tailored to community resources and divert people with SMI away from criminal justice involvement to the greatest extent possible Include emergency responders with knowledge and experience with SMI— including but not limited to schizophrenia, bipolar disorder, major depression, and other psychotic disorders—in both the planning and implementation of any emergency response models Enforce the bipartisan language in the 21st Century Cures Act that requires the Department of Justice and others to collect and regularly report data involving law enforcement encounters and mental illness Include racial and cultural demographic information in any data collected to inform future funding and policy decisions related to the treatment of mental illness, as well as reform efforts to prevent and reverse criminalization of SMI Make permanent all telehealth coverage for Medicare recipients that were expanded under Section 1135 authority during the COVID-19 public health emergency

Response 114:

Dear Chairman Wyden,

This plea comes too late to save my son, Guy, who passed away at the age of 25 from dual diagnosis. My son succumbed to death by accidental overdose of fentanyl after going of medication for schizophrenia, which led to his quitting his maintenance MAT for Opioid Use Disorder from prescribed drugs after a staph infection and subsequent wisdom tooth extraction.

Guy was a wonderful young man who began showing signs of SMI around the age of 14. He was prescribed antidepressants and anti anxiety medications, along with medications to treat ADD inattentive type. Later of course, we would learn that the ADD was a misdiagnosis and that he was on the spectrum; therefore, these meds I believe helped with the progression of auditory hallucinations and anxiety.

Around the same time, Guy would develop a painful staph infection on a family cruise. Once returning to port, Guy would be given an infusion of powerful opioids and sent home with them as well. A month and a half later, Guy would have his wisdom teeth removed. Of course, I compliantly filled the prescription of opioids to treat my son's pain… not knowing what was to come.

Fast forward to the next 9 1/2 years… my still soft hearted gentle giant of a son would spend his remaining years unable to get the necessary LONG TERM care he needed to treat his co occurring SMI and Opioid Use Disorder.
He is at peace now, but I can tell you~ his father and I will NEVER be at peace with the way this country has failed our most vulnerable. This is a bipartisan failure. It will take divine intervention and a true opening of the hearts to fix this~ and it must be bipartisan. Mental Illness and Substance use Disorder, Dual Diagnosis, should NOT be a political issue. This is a human issue. I beg you to look on the city streets and realize that as law makers, you are the only ones that can fix this.

Response 115:

Dear Chairman Wyden,
I've been a member of NAMI (in Marquette MI)
for over thirty years and have been fortunate to received reasonable services for my sons in the early stages of their illness, but as I've participated in NAMI support groups over the years I've noted the challenges facing many families caring for an ill family member. It seems that diagnosing mental
illnesses has improved but finding available services has declined.....from underfunding of mental health facilities and two few psychiatrists and providers. Our local law enforcement members have benefitted from
training but more and continued funding for
such programs is definitely necessary.
In areas where NAMI programs and support don't exist there is a need to help families both emotionally and financially.

Response 116:

Dear Chairman Wyden,

My 38-year-old son was arrested three times for criminal trespassing with a known history of schizoaffective disorder from the local mental health authority and still was put in the jail for his for his mental health illness. He never understood that he was violating the law and the police never explained it with a written copy that he could understand. When they asked him about the version to a mental health hospital he refused because heHas the diagnosis of our signature as well. This means he doesn't understand that he has a mental health disease. They knew that he did but yet they kept him in jail. This behavior on their part does not help the medley you'll get well at all!

Response 117:

Dear Chairman Wyden,

I respond to your inquiry as the parent of a son with a disability occurring before age 22 and a retired R.N. position, employed by the sate of Ct. When my state closed it's system, I was forced to have my son reside with me, as to not fall into any potential legal difficulties, now that the care network had closed. He has done well, never been hospitalized. Many parents are not able to perform this level of care, I was the exception. Now that I am close to eighty, my fears of his life's future are a daily occurrence without an adequate care service. For those with mental illness, the political camp had no consequences for their closing of healthcare services, as this population doesn't vote. their families have no education regarding mental illness, nor does the population as a whole. So this community has no concern about leaving them to the cruelty of others and has proved themselves capable of neglect with no humanity.
Thank you for allowing my input. All the recommendations put forth by the Treatment Advocacy Center would greatly decrease the neglect fostered upon this population, and their concerned family members, as well as active caregivers.

Response 118:

Dear Chairman Wyden,

I have lived with mental illness for 19 years. There are many times I cannot get treatment because of my health plan. It is vital to extend the number of inpatient days past 190.

Response 119:

Dear Chairman Wyden,

Hello. It's too difficult to understand all this political wording. I just want to mention that I have the bipolar disease and my brother has a schizoaffective/schizophrenia disorder. VERY, VERY SAD AND HARD TO UNDERSTAND AND MANAGE! It is very important that there be crisis intervention teams for ALL police and those who respond to a crisis. Most of the schizoaffective and schizophrenic people are already scared and do not understand the police intervention “techniques.“ The only place to take someone who has had and “experience“ with the police or others involved in a crisis intervention, is a hospital and not a jail. People affected by mental disorders/mind chemical imbalance MUST BE TAKEN SERIOUSLY! It’s very hard living this way. We need medication to be free or at least less expensive. My brother is injected every two weeks with Risperdal Consta. This should be free because it costs too much! For those who don’t have insurance or financial support, this is EXTREMELY difficult. That’s why we have so many homeless. They need to be treated and respected properly. Thank you very much and please take all of this into consideration because WE MATTER. THANK YOU. Blessings.

Response 120:

Dear Chairman Wyden,

I am an individual living with a mental illness, as well as, a counselor who has worked with individuals with severe mental illness for the past eight years. We need immediate help.
My clients are the ones who often "slip through the cracks" or "no longer eligible for services" or "tough cases." Because of this, I have seen clients churned into and out of the mental health system for years. And I have seen them die of unnatural cause before their time. This past week a colleague had to collect information about a former client of ours who had been found dead. He was 30 years old and had no significant health concerns besides schizophrenia. My clients will often disappear and then show up months later. The show up skinny, psychotic, and strung out. We cannot continue to ignore some of our most vulnerable citizens. And we can't we vague about it. Yes, #mentalhealthawareness is great. We all need it, but we need stop ignoring individuals with severe mental illness. The guidance from the Treatment Advocacy Center will begin to address concerns. I urge the Senate Finance Committee to support the issues address in the letter.

Response 121:

Dear Chairman Wyden,

The US discriminates the mentally ill by enacting the IMD exclusion. I am a Family Physician who has spent the last 18 years attending to those living on the streets. My biggest heart ache is seeing the SMI homeless living in their filth amidst feces, urine, vermin in and out of jail unable to be properly cared for. Medicare and Medicaid must pay for the mental stablization ang long term care for these most debilitated population. It is truly our dirty little secret and time to care for them properly with qualify board and cares that provide "radical hospitality" - Housing that Heals!

Response 122:

Dear Chairman Wyden,

Police are needlessly overburdened by the mentally ill abandoned by the mental health system A FIVE-PART PLAN TO ADDRESS SERIOUS MENTAL ILLNESS (SMI)

1. RECLASSIFY SERIOUS MENTAL ILLNESS (SMI)) FROM A BEHAVIORAL CONDITION TO WHAT IT IS, A NEUROLOGICAL MEDICAL CONDITION

WHY RECLASSIFICATION IS IMPORTANT

Reclassification will unlock more research funding and help eliminate discrimination in treatment, insurance reimbursement, and the perception of SMI as "behavioral" condition. SMI is a human rights issue. NIMH ranks SMI among the top 15 causes of disability worldwide with an average lifespan reduction of 28 years.

2. REFORM THE HEALTH INSURANCE PORTABILITY AND ACCOUNTABILITY ACT (HIPPA)

WHY HIPAA REFORM IS IMPORTANT

Overly strict HIPAA laws make it extremely difficult for families and caregivers to partner in the treatment of their loved ones, resulting in important life-saving medical information gaps. By eliminating this barrier, family support will be strengthened, reducing the chance of relapse, homelessness, imprisonment, and death.

3. REPEAL MEDICAID'S INSTITUTES FOR MENTAL DISEASE EXCLUSION (IMD)

WHY IMD REPEAL IS IMPORTANT

IMD repeal will increase the availability of psychiatric inpatient beds. The IMD exclusion is not only discriminatory of those suffering from neurological brain disorders, it is a leading cause of our national psychiatric hospital bed shortage. It prohibits Medicaid payments to states for those receiving psychiatric care in a facility with more than 16 beds who are 21-65, the age group with the most SMI.

4. PROVIDE A FULL CONTINUUM OF CARE

WHY A FULL CONTINUUM OF CARE IS IMPORTANT A continuum of care insures that SMI patients receive early intervention at all stages of their illnesses, long- term care when needed, and follow-up treatment (medications and therapies) when they're released. It reduces visits to jails, ER's and hospitals, homelessness, and morgues. A continuum of care provides life-time management.

5. DECRIMINALIZE SERIOUS MENTAL ILLNESS (SMI)

WHY DECRIMINALIZATION OF SMI IS IMPORTANT People suffering with other neurological conditions like Alzheimer's and dementia can get treatment promptly without being kicked out of their homes to wander the streets until they are arrested and put in jail or prison rather than a hospital. Serious mental illness is the only disease where the doors to treatment are shut unless a crime is committed. This is pure and simple discrimination with the disastrous results we see in our country today — homelessness, incarceration, the disintegration of families, and death.

* Work with legislators to change "must be a danger to self or others" criteria.

* Work with legislators to change involuntary commitment criteria, alleviating the subjective nature of "gravely disabled" and redefining it in objective terms based on scientific medical need for treatment. Psychosis, like a stroke, is a traumatic brain injury and needs immediate treatment for the best outcome.

Response 123:

Dear Chairman Wyden,

Schizophrenia son 31 who I cant get help for. I am his guardian and still cant get help for him. He takes no meds, his hygiene is terrible and not eating well. 72 hour hold doesn't help, please help us parents who want to help. Tired of dealing with court system also. He is not a criminal. I had Crisis come over recently, nothing they can do. Please help fix this serious mental illness

Response 124:

Dear Chairman Wyden,

My son is 24. He has been in an AOT for 23 months in upstate NY. He has been in an apartment, and safe since he has been in the program. He has been in contact with me, in a loving way. He has friends and 2 pets that he is able to care for. He is not happy that he has to take the medication, and he doesn't believe he has schizophrenia. He says he will stop the meds as soon as the AOT is done. Previous to the AOT, he was hospitalized 10 times over 3 years. He was evicted from his apartment and he lost several jobs. He threatened several people including roommates, landlords, and family. He believed everyone was trying to hurt him including his parents. He saw and heard things that weren't there, and was unable to differentiate from reality. He had many delusions of supranational ideas. I can go on. His treatment is his only hope for a somewhat normal and safe life. Unfortunately, he would not choose this for himself. This is my son. I love him with all of my heart. When he is not on treatment, I cannot be near him. This is the cruelty of his disease. Please know that these people are human beings with families. They deserve treatment just like anyone else. They are not capable of making safe decisions on their own, because they are suffering from a brain disease. Please help them.

Response 125:

Dear Chairman Wyden and Ranking Member Crapo:

I am delighted to learn that the Senate Committee on Finance is seeking input from the public to assess factors contributing to gaps in care for people living with mental illness. I would like to share my family's personal experience with the mental health system and offer possible policy solutions.

My family was unable to get treatment for my brother with schizophrenia because he had a lack of insight into his own illness, known as anosognosia, which is the most common reason people with serious mental illness do not accept treatment. Because we could not get him treatment, he deteriorated, suffering from terrifying delusions, auditory hallucinations, personality changes, and an inability to have relationships, hold a job, or even to perceive reality. For people like my brother, who had Medicaid, the only way for them to receive effective treatment is after a tragedy has occurred, and that's exactly what happened in his case. Once in long-term inpatient treatment in a state hospital, he regained insight and reconnected with family. After discharge, he continued treatment on an outpatient basis and became a productive member of society, volunteering for NAMI and serving on the board of directors and working as a peer in assertive community treatment for people in crisis. He also was able to marry and have a family. However, the amount of suffering he and my family experienced due to his lack of treatment and later involvement in the justice system was tremendously damaging and traumatic. People should not have to deteriorate to the point of tragic outcomes in order to become eligible for treatment.

To address the wide-ranging problems that create a woefully inadequate mental health system, Congress must expand federal funding for assisted outpatient treatment (AOT), which helps individuals with serious mental illness who do not have insight into their illness to access treatment. Assisted outpatient treatment could have saved my brother and my family from the horrible consequences that happen when serious mental illness is left untreated. In addition, Congress must fund programs to help divert people with serious mental illness away from the criminal justice system.

Another family member, my nephew, has also experienced mental health crises. As a minor, he spent days boarding in an ER while waiting for a psychiatric bed to become available. Beds are limited due to the Institutions for Mental Disease (IMD) exclusion, which limits access to inpatient treatment beds. Congress must repeal this discriminatory, misguided law. No other type of disease or illness limits the number of beds available--this is discrimination, plain and simple. The Medicare 190-day lifetime limit is also discriminatory.

Once my nephew was discharged, he was back in a system with not enough providers, resulting in weeks-long waits for a psychiatrist appointment. Permanent telehealth coverage could help. Now that he is an adult, we are unable to engage him in treatment. I am fearful that he will follow the same path as his father (my brother).

Finally, I was flabbergasted to learn recently that the National Institute for Mental Health inexplicably revised the prevalence statistic for schizophrenia with no new research or data--their new estimate eliminated 2 million people with schizophrenia. This absurd change was reported in the Wall Street Journal in an article titled "Where have all the schizophrenics gone?" Because research and funding budgets are based in part on prevalence, this change, about which NIMH showed no transparency, has a deleterious effect on funding for new treatments and programs that are so desperately needed for people with schizophrenia. NIMH should be required to base prevalence on data and show transparency in how it determines its estimates.

There are so many other families like mine who have faced barriers to treatment. These are just a few examples of reforms that must be made to the mental health treatment system. Thank you for the opportunity to share my comments and proposed solutions for inclusion in your legislative package.

Response 126:

Dear Chairman Wyden,

American's with Serious Mental Illness may only represent 2% of the US population. Yet untreated SMI costs society greatly in resources for police, jails, emergency room visits, inpatient hospitalization, lost income from lack of employment of the individual and their family member who is left to care for them. My family experienced extraordinary stress due the years of lack of appropriate medicine to help my son with SMI. We need more research on appropriate medicines- especially those who are mediation resistant (meaning they metabolize the medicine and it is no longer effective), increase the utilization of clozapine and appropriate protocols, involuntary treatment when incarceration due to symptoms is the alternative. Please help families like mine. Clozaril was finally effective but no psychiatrist was willing to take his challenging case or offer that medicine. It was a game changer. He is now working, off disability and getting his life back after nearly 6 years of arrests, jail, hospitals, = failed treatment. People should not be in jail when their medicine isn't working and society doesn't have good doctors willing to care enough to try an effective medicine.

Response 127:

Dear Chairman Wyden,

I succumbed to serious mental illness (SMI- schizophrenia) back in 1979 resulting in terrible tragedy in my family. I went to trial but was found Not Guilty by Reason of Insanity. I am spending the rest of my life in the Courts. The full story is in my book In the Matter of Edwin Potter: Mental Illness and Criminal Justice Reform.

Fund programs that are tailored to community resources and divert people with SMI away from criminal justice involvement to the greatest extent possible.

Response 128

Dear Chairman Wyden,

I am the mother of an adult son with schizophrenia who had his first psychotic episode at age 21 while a student at USC. Only 10 years later he reached his 190 day lifetime limit for Medicare funding.. As a result, for the past 25 years, no free standing psychiatric hospital in San Diego would accept him for inpatient treatment. PLEASE REPEAL THE MEDICARE 190 day lifetime benefit. Limiting funding for severe mental illness, a brain disease, is discriminating and unjust! .Isn't the brain part of the rest of the body?

Response 129:

Dear Chairman Wyden,

My family has yet to be able to get mental illness treatment for my brother who is blind, physically disabled, and has Schizoaffective w Bipolar Disorder and Anosognosia, or "lack of insight" or "awareness" of his serious mental illness/brain disorder because he does not know he is ill. In some cases, like my brother – he does not always perceive reality. The only way for him to receive effective treatment is after a tragedy, and that is exactly what happened in his case.

He was struck by two different vehicles in a 4-month period - resulting in critical injuries and requiring a year of post-acute care. He was released back to the streets in our county using the county building address in his hometown on his hospital discharge papers as his "place of residence" and so when the social worker from Adult Protective Services (APS) didn't show up to 'receive" my brother, (a supposed scheduling mistake) Mark was left sitting on the wall by the county building where he felt safe. A year later, my brother, Mark is still on the streets... disabled physically and mentally, totally and completely blind, with voices that he hears and converses with... at times highly agitated, unhealthy, unclean, illnesses and injuries, pain and temperatures, wet or dry, his stolen meds that he was released with a year ago never replaced although many agencies and social workers were aware that he had been robbed of all his medications within 3 days after being released to the streets - a year ago.

For people to be eligible for treatment, they should not have to deteriorate to the point of tragic consequences. A man has slept on county property for fourteen years. I think everyone in the area knows who he is or has seen him, read about him in the newspapers or followed us on social media for our local community. There are so many families like ours that are shattered and battered as family caregivers. HIPAA regulations prevent family members from participating in the entire medical field, so they have no input or knowledge about medication regimens, which more often than not result in yet another tragedy. Immediate family members should be included in the care and treatment plan of someone with serious mental illness including anosognosia in a similar way to the inclusion of family for Alzheimer's, Dementia, or Parkinson's.

AOT, which helps individuals with serious mental illness who do not have insight into their illness to access treatment. A patient with known anosognosia, delusional or with psychotic symptoms cannot be hidden but is seen daily in our hometown as doctors, social workers, lawyers, psychiatrists, police, even media at times drive by my brother on their way to or from work. He is not the "town secret." There is however - enough shame to go around. Not my brother's shame. Not our family who has attempted to get him help and who have spent years trying to get a "public guardian" appointed by the County of Solano under the LPS act and have been stone-walled at every turn…Not our 81-year-old mom applying for AOT through Laura's Law in January 2020 only to be turned down.

The improvement in Mark was evident during his post-acute care when he was cared for and getting daily treatment including antipsychotics for the first time in 3 decades, and his complete deterioration since being ignored once again is also evident. Because he is an adult, we are unable to force him into treatment. About 50% of people with schizophrenia, bipolar disorder, and schizoaffective disorder also have anosognosia. It is a major barrier for many families who feel they have nowhere to turn.

I have watched in awe while some who have been good Samaritans helped us keep Mark alive in the only ways, we are allowed to under the laws, though we also still feel shocked at the lack of urgency to help for those with severe mental illness and those who are homeless on our streets. We have watched our friends and other family advocates lose their young adult children to suicide at home and on the streets and seen other mortality factors that come with serious mental/brain disorders. Those of us with loved ones with serious mental illness/brain disorders are caregivers who have no authority. Up to half of the homeless population have some form of mental illness. On the other hand, most of our population of the seriously mentally ill either have been or still are incarcerated as if that is the type of treatment they need or deserve.

My family worries every single day how my brother is living and dying right out in the open for all to see. He has the civil right to die on the streets and is protected but those not living in the chaos that can ensue insist - it is his choice. But he cannot make a choice without having all the facts. People with anosognosia do not comprehend or are even cognizant of having a mental or brain disorder. That is what is missing. And yet they are still expected to make decisions with capacity and informed consent. His right to die is more protected than his right to treatment even if he doesn't know he needs it.

There are so many other families like mine who have faced barriers to treatment. These are just a couple of thoughts about needed reforms to our mental health treatment system. I appreciate the chance to offer my comments about proposed legislative solutions and hope that the SMI/SBD population will not continue to be pushed to the back of the room, the back of the line, or out to our streets when it comes to getting needed treatment. Where are the psychiatric beds? End the IMD exclusions and fund more beds besides the ones in jails and prisons. It has been more than 60 years since our mental health system transitioned from institutionalized asylums to community-based access to treatment and care. But we have yet to meet that objective.

Response 130:

Dear Chairman Wyden,

Homelessness is a symptom, not a root condition. In my observation, based on personal experience at the family and community level, there are two radically distinct levels of homelessness; those unintentionally without shelter who are trying to get back to a sheltered situation but are impeded by financial situation. These individuals and families will take whatever steps they are able to obtain shelter. those who become homeless due to a variety of circumstances, generally mental health and/or addiction-related. These disadvantaged individuals are often not able to navigate the complex services and options that might become available and are likely to become chronically homeless finding it easier to exist on the streets as urban campers. Many, if not most of the chronically homeless suffer from mental illness and/or addiction. Addiction is a disease, as are the many mental health diagnoses suffered by the Homeless.

I sat on the HIP board in Broward County, FLorida & have worked with homeless issues for years, in Florida, Texas, and Massachusetts. I was also a caretaker for my brother in the last 5 years of his life, which ended much too soon after years of suffering through a system that did not provide the support he desperately needed. . The significant impediment is the absence of treatment for mental health or addiction issues when the homeless are placed in housing. They often do not have the mental capacity to solve their addiction and related health alone. Like many of our homeless, they become regular patients at the local Emergency rooms, with no tracking or follow-up. If they suffer a mental illness, there is no permanent support situation to assure they receive the care, counseling, and medical management they need. Addiction is a powerful illness but is not recognized as such. They do not choose to be an addict but are offered no supportive treatment to manage the disease. The very nature of the disease predicts that they will slip up while moving forward in the healing process.

Until there is permanent supportive housing that does not require they stay clean and sober, they will deteriorate into chronic homelessness. The longer these individuals are on the street, the less likely they will be to ever get off the street. That is statistically shown in any study you find on the chronic homeless. Without understanding the needs of the mentally ill and addicted, there will be no solution to the “Problem” of homelessness. It is a sad fact that most people probably don't have the experience to comprehend the situation, yet there is no shortage of opinions!

An addict doesn't choose that life. They don't generally have the tools to beat it on their own. Couple that with mental illness and no income and try to imagine the options you would have for salvation. The homeless who "don't want to be housed" generally don't have the tools to see their way clear to supportive housing. Until the powers that be, provide the permanent supportive services to help, the odds for success are ZERO. Homelessness is a symptom, not the root problem. It’s like taking aspirin for a headache - the headache temporarily vanishes but you have not addressed what caused the headache!

Like the majority of the general public, the attitude towards addicts is that they need to solve their own addiction problems before they “deserve” help. They cannot solve mental illness and/or addiction without help. Society doesn't offer them the help they need. They are in a brutal Catch-22. The fear in this discussion is that if we make it too inviting for the homeless to live here, we will open the door to the nation's homeless population. That is an apt prediction if the root cause is not addressed.

Response 131:

Dear Chairman Wyden,

My loved one was diagnosed with schizoaffective disorder. But this was not until a year of unemployment, paranoid psychotic behavior after his medication change. Because he could not hold a job he did not have easy access to medical care. He was unable to make or keep appointments. He began to believe conspiracies about everything that was around him. His family and I lived in constant fear for his safety and ours but the healthcare and legal system said he had to have more severe decomposition. So we had to see him engage in violence, property damage and homelessness until the police could see that he was gravely disabled enough for hospitalization. He has now been hospitalized twice, most recently for trying to commit suicide yet he still is non medicated and his family can do nothing to help. He had a bright future in front of him but because of his lack of awareness of his condition that has been dimmed and he blames himself. Please help get treatment to those who need it and not make them wait until it gets so severe and heartbreaking. Listen to a patients loved ones and understand the patient may not have full awareness of what is truly happening in their brain. We really do need reform and funding to save lives and help people with severe mental health conditions survive and thrive.

Response 132:

Dear Chairman Wyden,

I have experienced the worse side of the mental health crisis with my daughter. You see, my daughter suffered a traumatic brain injury at age 12 after being hit by a drunk driver while riding her bicycle. She was subsequently diagnosed with both PTSD, Anxiety, and a seizure disorder. Long after her physical injuries healed, the scars left mentally still remain. Years of treatment, when she hit her teenage years she started abusing illegal substances, as a way to cope. For the last ten years, her addiction has taken my family for a roller coaster ride. This year my daughter experienced her first bout with psychosis. I tried to get her medical help without law enforcement intervention and that was a fail. She presented to an emergency room in the OKC metro and relayed that she was both suicidal and homicidal and was was not treated. She was released to the streets. So that resulted in our next attempts in getting her assistance utilizing CIT officers to get her admitted. I wish things ended there. Sadly it did not. As her condition progressed and of care by medical staff ensued, the situation became life threatening. Sadly, she has had to be disarmed 4 times in attempts to do harm. The last time the police officers that responded to her attempt to stab my husband to death in his sleep, did not even write a police report. Instead they instructed her to go to sleep and if they had to come back out to the home they would have to "take her in". Eventually I was able to get her some help. She was admitted to a stabilization hospital, went before a mental health court, and was ordered to be involuntarily committed to the state hospital. Sadly, the hospital was full, so she was released back to the streets. Now under a guardianship, my family spent 15 days looking for my now reported missing daughter. When found by local law enforcement, she was apprehended for an old driving offense. Since that time she has been in the County jail for Oklahoma City. It is unbelievable that this is the safest place for her to be, as she is unable to harm herself or anyone else and receives her medication. The jail is one of the worst in the country, yet that was the best option for my daughter in a mental health crisis. I know there has to be more, better options to treat a mental health crisis, but right now the mental health system is so broken I do not see how you can revive it on the state level. In my opinion, the federal government needs to step in, complete a full audit of where funds are going that are allocated for mental health treatment before anymore funds should be released to the States. My story is sadly not unique. Parents from all over the Country have reached out to me and shared similar horror stories. Please establish a national office that both manages and monitors psychiatric treatment. Enforcement against the mental health hospitals that fall below standard is essential. Currently, in Oklahoma the Department of Mental Health and Substance Abuse is suppose to monitor standards and enforcement treatment standards in the State, but from my experience, they have failed miserably. We must repeal the Medicare and Medicaid 190 lifetime limit. Honestly once someone has experienced psychosis the likelihood of subsequent episodes is almost expected. The one treatment center that my daughter attended, a psychiatric hospital in Tulsa, requested 180 days and insurance denied that request, rather they agreed to 90. It was not long enough and had she completed the time requested by the hospital she may have avoided ultimately deteriorating to the point of catatonia, which is life threatening. If there is someone actually monitoring that providers are meeting standards and enforce any discrepancies, then the doctors, not insurance, should be able to prescribe what is in the best interest of the patient without fear of nonpayment by the insurance. It is essential that we establish federal funding for assisted outpatient treatment, but only once there has been a full audit and safeguards in place to ensure that the funding will not be misused. States that follow the guidelines and cooperate with the audit should be rewarded. Maybe they receive incentive pay, as a way to encourage other state agencies to comply. Finally, include emergency responders with knowledge and experience with SMI— including but not limited to schizophrenia, bipolar disorder, major depression, and other psychotic disorders—in both the planning and implementation of any emergency response models.

Response 133:

Dear Chairman Wyden,

My 24 year old son has had repeated hospitalizations for psychosis. I have had to leave my teaching job to care for him due to the lack of supportive housing . Why do we not care for our citizens with brain illnesses ? I am terrified he will end up homeless and I have no idea what will Happen to him if I get ill or when I die . There are no other family members to care for him. Please repeal The IMD exclusion and support programs For long term affordable housing for people with mental Illness .

Response 134:

Dear Chairman Wyden,

I am the mother of a beautiful young adult whose life is permanently changed by bipolar. Schizoaffective SMI. A symptom of this brain illness is anosognosia, or lack of insight. His biggest barrier to help is the handcuffs those who love him wear, otherwise known as HIPAA. My son is homeless. Penniless. Severely ill in Anchorage AK. He is stuck.. my view on the face of homelessness has forever changed. Not beggars, they are ill. LOST. And the hippa laws that were intended to protect- harm our loved ones. Mental Illness and schizophrenia in all its forms is a cruel diagnosis which our system barbarically ignores those with the most need. AOT is proven to save our sons and daughters. For my son, I can only pray for him - thousands of miles from his home. There us no sadder story than the family living with SMI and the helplessness we are forced to endure because of our nations laws and funding for specialized housing, treatment and understanding. It is mourning the living each and every day.

Response 135:

Dear Chairman Wyden,

The mental health care system is broken beyond repair. It needs to be dismantled and the new, more humane and compassionate system created.
1. Abandon or greatly amends HIPPA law so family members can freely advocate for their loved ones 2. Have the therapists and psychologists trained in open dialogue and how to talk to people in distress /how to de-escalate without drugs work in the psych wards so they ask the patients “what happened to you.” Instead of “what is wrong with you?”
3. Make the length of treatment depend on the patient’s needs and not insurance /profit 4. Start with the minimum dosage of the dangerous Psychoatric medications, and increase if needed.

Prescribe the best medication possible with the least side effects, regardless if insurance covers it. The treatment should not depend on what insurance covers; it should be the best possible treatment in every case. Extend the stay if needed. Stop “catch and release” practice. Never discharge people to the street or homeless shelters! How are they supposed to get well being homeless?!

5. Treat patients with dignity; allow men to shave, even if it has to be supervised.
6. Train social workers how to find a reputable step down program, not just “anything” to get rid of the patient.
7. The psychiatric hospital is a very traumatic experience for the patients. Do anything you can to make it less traumatic. My son had PTSD from the hospitals.

Response 136:

Dear Chairman Wyden,

Ensure access to inpatient psychiatric care for acute and long-term treatment needs as an essential component of an appropriate continuum of care. States need to reopen & open State run, accredited, fully trained & staffed acute, locked, unlocked, LONG TERM professional STATE PSYCHIATRIC MENTAL HOSPITALS!!! We need HOSPITALS not Clinics!!!

Response 137:

Dear Chairman Wyden,
Please include emergency responders with knowledge and experience with SMI. My adult son was arrested and taken to jail in Butte County CA It when he was experiencing a psychotic break. It wasn’t recognized by the officer. Now he refuses treatment.

Response 138:

Dear Chairman Wyden,

In honor of my intelligent beautiful son who's life has been altered and robbed immensely due to Paranoid Schizophrenia....

1). Codify that doctors (NOT insurance companies) decide length of stay in acute hospital beds and other step down levels of care, and that insurance needs to cover this just like they would if the person were there for cancer or heart care.

2). End the policy of stopping SSI/SSDI for people who are hospitalized 30 days or more. Just because they are sick and in the hospital, it doesn’t mean their rent or mortgage isn’t due. This is but one of the paths to homelessness. Believe me, we have seen this happen.

3). Allow HUD to subsidize housing all along the continuum of care including residential treatment facilities, group homes, sub-acute care units and stabilization facilities. We know that just subsidizing housing alone, with no tie to integrative treatment doesn't work. So, subsidize the treatment facilities all along the continuum of care that are barely surviving financially, and then, they can serve more people.

4). Of course, end the IMD Exclusion.

5). Fund provider education about HIPAA regulations so that MH professionals will communicate with families just as they would if we were supporting an elderly parent or grandparent with Alzheimer's or Dementia. If we can recognize this is appropriate for elderly with one form of a brain illness, we surely should be able to have this be common practice for our adult loved ones with a different type of brain illness.

6). Fund AOT(Assisted Outpatient Treatment) Programs, and Civil & Criminal Mental Health Courts to divert people to treatment, not jails and prisons.

7). End the Medicare & Medicaid Lifetime Caps for inpatient treatment for people living with brain illnesses. These illnesses are chronic and episodic. To limit treatment for these people is cruel, inhumane and arbitrary.

8). Allow for people in the criminal justice system to have Medicaid Insurance. Too many cannot get the most effective medications and treatments, as the ones they can get depend upon the budgets of the correctional systems in their counties and states. And, not having insurance when people are released, and still on probation and/or parole, is one of the reasons they are not treated and sometimes re-offend.

9). Raise reimbursement rates for Mental Health Professionals AND Direct Care Staff.

10). Fund Psychiatric Assisted Living Campuses with multiple levels of care from acute care with First Episode Psychosis Programs, to sub-acute care, to independent living, to supportive employment, etc. We have similar facilities for our elderly with Alzheimer's and Dementia. We could have these for adults with these different types of brain illnesses.

11). Fund Loan Forgiveness Programs for MH Professionals including psychiatrists, psychologist, MH counselors and therapists, and family practice doctors, Nurse Practitioners and Physician Assistants who get certified in Psychiatric Medicine.

12). Fund more CCBHCC's (Certified Community Behavioral Health Centers). Having more financially viable providers of mental health care allows them to expand staff and services and provide care to more people.

13. Change the criteria for in home support. In the state of Alaska my son does not qualify for in home care and support because he was not diagnosed with a childhood brain disorder. Such as Attention Deficit Disorder. Although he did have ADD, I as his mother had no idea what was wrong

14. Schizophrenia and similar brain disorders should be reclassified to the neurological brain disorders/diseases that they are.
The Behavioral health label needs to go, as the disease causes the behavior!
Which in turn is the problem of being denied support services and care.

Response 139:

Dear Chairman Wyden,

I am writing to you today with input on the bipartisan mental health package. I am the mom to 2 boys adopted from the foster care system. In the 10 years we have been together, I have desperately sought mental health services for them. Many of these services exist on paper but in reality aren't available due to work force shortages and/or poor Medicaid reimbursement rates.

Please consider loan forgiveness programs for mental health professionals. Also please consider higher reimbursement rates on mental health services so families like mine can actually get access to the services we need.

Response 140:

He was a wonderful person. Even in illness he was very sick and terrified but had courage at the same time. Early on being so paranoid and no medication he he came to me and said, "As bad as my life is Mom I want to live." I was so thankful that he wanted to live. It was a rough road ahead for the next 13 years. At the time they only had Hadol which made him zombie like. He hated the medication and always asked the private psychiatrist to reduce the medication. Within a few weeks he would be psychotic again and we would have to in-voluntary commit him. Other times he would disguise the fact he had taken medication (he became a master at this) but always end up psychotic again and would need to return to state hospital. This was our life over and over always looking for better treatment. I would walk in on him begging the voices to go away and leave him alone. Not till 1997 did we find the right medication Clozapine.
The Clubhouse model a program from the Fountain House in NY, NY is a wonderful less restrictive environment and my son got to remission because of the psychiatrist there and the fact we could share information. This cannot happen today because of HIPAA law. So glad I sent him to Life Help.

Response 141:

Dear Chairman Wyden,

Please help Treatment Advocacy Center and families like mine to manage the maze of directing people with serious mental illness through a life worth living. My son has had scizophrenia for 20 years. He has been in the loop of homelessness, hospital stays, and jail terms repeatedly for most of these years. He moves to a different setting about every other month (on average). The only time he has been in any kind of stable situation was during the year of his Assisted Outpatient Therapy mandate (8/13/20-8/13/21). When he is court ordered to take his meds by injection, we see a little light of hope. He goes into a rehab for drug and alcohol use, and comes out able to work (part time), able to live in a boarding house without being evicted, and he has positive interactions with family and friends. When he is not mandated to take the long term injections, he drinks and drugs, tags public property, wrecks his car, screams obcinities, and is not able to work or live in any housing near anyone. It is sad, to say the least! His mandate dropped in August. If he were in New Orleans, we could have it extended (They have a judge dedicated to mental health court. They have doctors and lawyers who understand AOT law, and they have active advocates for mental health). In Baton Rouge, he is not contacted by the court. He is not held accountable for taking the meds. There is not a dedicated judge for mental health. There are not attorneys who understand the law (even though we are in the same state, with the same laws). We do have advocates, but their hands are tied with so little to work with on AOT plans. Imagine the difference it would make in out society if all of the scizophrenics were on the proper meds. Imagine the hundreds of thousands of tax payer dollars that my son alone has cost our system without these mandates for over 20 years! Imagine multiplying those hundreds of thousands of dollars, by the hundreds of thousands of scizophrenics. My son's bills and records come to my address (his permanent address, though he can not live with me). I see the mega waste going on by his repeated times in hospitals and rehabs, not to mention the jail times. Please help us to help him and the many, many people affected by this terrible disease (patients, families, and tax payers)! We can do better as a society. New Orleans has a good thing going, but that judge is retiring soon. All of our cities should have a judge like Judge Reese. He should not be a lone star in our state. Please expand mental health policies and laws to include these recommendations in all cities, in all states, all across our menatlly ill ravaged country. Thank you!

Response 142:

Dear Chairman Wyden,

I am the mother of an adult son
Who has schizophrenia.
Because of the anti psychiatry movement Services are badly affected.

Response 143:

Dear Chairman Wyden,

My family most desperately begs the USCF to consider the TAC's letter of recommendations. Here in Johnson County, KS, there is no safe, comfortable, non-threatening place for a family to take their loved one who is in an SMI crisis other than a hospital emergency room (ER). The letter references ER warehousing of patients in SMI crisis, and that's awful, but the fact not mentioned is the number of crisis patients who are NOT admitted without having harmed themselves or others. This distinction removes any hope the family has of finding immediate treatment, almost to wishing their loved one WOULD exhibit harmful behavior. Can you imagine being in that predicament? It is hell.

PLEASE, do whatever is possible to commit more funds to local mental health facilities so they can provide emergency facilities strictly for SMI situations. Likewise, anything you could do to provide funds to support education/training for more mental health workers would be wonderful. The days and nights our family has suffered under the current situation of nowhere to turn, nobody to treat is untenable.
PLEASE act now on the TAC's proposals.
Thank you very, very much for any help you can provide to my family and my community.

Response 144:

Dear Chairman Wyden,

HIPAA is one of the main reasons my Gravely Disabled brother remains today on the streets of Vacaville, CA. He is100 % blind (lost eyes in accident) Had a massive TBI (frontal Lobe). He then developed Schizoaffective Bipolar Disorder a few years after the accident. He does not believe he is mentally ill. Even through over 60 surgeries, (many brain surgeries) Most doctors would not talk to our family due to HIPAA. My brother was already exhibiting his Anososnogsia. That coupled with HIPAA...is a recipe for disaster. He immediately developed an oppositional behavior towards the family and any legitimate offer for MH Services. He will not sign any ROI's. He will not give permission to doctors or agencies to tell family what his options for treatment are, or how they can help. He refuses all evaluations, medical care and shelters for 14 years now. HE is gravely disabled, physically disabled, brain damaged, and mentally ill, but HIPAA has maintained his "So called rights!" So how have those "rights" benefited him? HIPAA has directly been responsible for preventing our family from seeking proper MH Services and continues to prevent us from having our County appoint a Public Conservator to my brother. HIPAA is contributing to the many SMI/SBD on our streets who are suffering and dying when there are families of the gravely disabled and SMI that are being blocked and prevented from helping their loved ones......probably the only ones that truly want to find them help. Where the SMI and the gravely disabled are concerned HIPAA has done more harm than good and has caused more despair for their families by tying their hands at every corner. My brother will die soon on the streets. Please consider a revision in HIPAA concerning the SMI/SBD and the gravely disabled. Serious Mental Illness needs to be reclassified as a neurological disease and treated as such. Serious mental illness needs to be decriminalized. What other illness do they say that the patient must harm themselves or others before any involuntary treatment? What other disease sends the patient to jail rather than a hospital? Please address HiPAA reform. Please repeal Medicaid's IMD exclusion. Provide a full continuum of care. My brother deserves more than the "right to live or die on the streets", but not the right to treatment for a no fault brain disorder. I have tried to care for my brother for 14 years as an American Curbside Caregiver with the U.S. Mental Health System blocking my every move. Decades of outdated laws have sent our SMI/SBD loved ones to the streets, our jails, and our morgues.

Response 145:

Dear Chairman Wyden,

1) Please expand federal funding for assisted outpatient treatment (AOT)! If AOT had been an option for my son (who has SMI) he would likely not be in jail now. This is SO important in saving lives - and family anguish.
2) Please request a Government Accountability Office (GAO) report on the extent of psychiatric boarding in emergency departments in the U.S. My son has been boarded up to five days, while severely ill, and often in restraints. Horrible to witness and should not be happening. A GAO report could highlight the problem and perhaps lead to oversight/change.
Thank you!

Response 146:

I am a 70 year old mom and caretaker of my 27 year old daughter. The system is so broken I don't know where to start. She has suffered from severe brain disorder since early high school. She has been admitted to the " drive through psych admissions"

(I've lost count) at least 15 times and in many different states. She's hitched rides and gone to many states. Last state was in Nebraska's jail. Disorderly conduct and resisting arrest. She had been missing for 2months she left her ID and glasses at a shelter in another town in Nebraska and they sent a post card telling her they had them at a police station. She ended up in ny by interstate compact at

Rockland county psych hospital. That was the only long stay at a psych hospital. She came out in a better state of mind. And on AOT.

Most seriously Ill patients are discharged too soon only to return to the hospital or jail. Housing is a crisis Long waiting lists. Takes almost 2 years to get to start looking for subsidized housing. Most apartments are really in bad shape. My daughter was shown one that was a converted small motel room. Very small refrigerator. No stove or oven. Just a portable plug in with my 2 burners.

There's a long wait for programs as well .

She was hospitalized for attempted suicide. Staff finally convinced her to call me and let me know the situation. Hippa law is ridiculous . Family has no rights to know what the status and plan is. If her brain disorder was Alzheimer's that would never be a problem. A psychotic patient be treated any differently from an Alzheimer's patient.

Please get the funding to take care of these people. The system is so broken. How can these unfortunate people with serious brain disorder but be neglected and treated so poorly.

Please get more funds to support these people.

Response 147:

To the US Senate Committee on Finance,

My daughter Annabelle Bricker attended Emory University and New College of Florida, graduating with a focus in Math.

Among other accomplishments, she was on the governing board of United Methodist Women, and opened the international General Assembly of the United Methodist Church in 2016.

Soon after that she began hearing voices, and at twenty-four had her first psychotic episode. Twenty-four is the typical age of on-set Schizophrenia for females, and, sure enough, she was diagnosed with Paranoid Schizophrenia in early 2017.

Over these past four years, her father and I and numerous others have called 911, our only crisis-response resource here in the Keys. The results have included two arrests, and six involuntary commitments. The first time Annabelle was arrested, neither my husband and I, nor the law enforcement officers, as compassionate as they were, knew to refer her to a First Episode Psychosis Treatment program which could have changed the trajectory of her life.

The second time we called 911, in hopes of getting her Baker Acted, the officer said he had no choice but to arrest her because of a Monroe County policy that mandates arrest when someone is involved in a domestic quarrel. So she went to jail. In an ill-advised tough love posture, we refused to bail her out for three months. In the Monroe County jail, Annabelle met two real criminals, who later took advantage of her. One young woman even tried to steal her car and beat her up.

Thankfully, Annabelle is now stable and living at home where she feels safe with me and my husband. However, she is unwilling to leave her "Awesome Airstream" and she is no closer to living a normal life than she was at twenty-four. Because of lack of insight to her own illness, she refuses medicine and therapy. And, the most telling thing about her experiences of the past four years is that now her recurring delusions, hallucinations and paranoia revolve around law enforcement and being arrested.

For example, this past week, my reclusive Annabelle agreed to go get vaccinated. But at CVS, she imagined SWAT Teams coming down the aisle to get her. As we quickly left CVS, she told one of her imaginary friends that she might as well commit suicide. It was a moment I desperately wished I could call 988 and have a Mobile Mental Health Crisis Response Team summoned, but since our only recourse here in the Keys is to call 911, we returned home and I hoped for the best. A law enforcement response only exacerbates Annabelle’s paranoia, and either results in an arrest or a three-day involuntary commitment, neither of which make any lasting improvement in Annabelle’s condition…and costs society needless dollars.

Our society certainly needs law enforcement. In fact, I believe law enforcement officers should be paid more, not less. But, officers in uniform with guns on their hips, mandated to arrest those involved in a domestic quarrel, lacking knowledge of the state-of-the-art treatment options, are not appropriate first responders to a mental health crisis for individuals with Serious Mental Illness.

Please, in your wisdom, help change the mental health system to better serve those living with a Serious Mental Illness. Our current system is expensive, ineffective, and cruel.

Key Largo, Florida

PS Our Upper Keys community held a virtual symposium "Re-Imagine Crisis Response" featuring the Sheriff, Allison DeFoor (former Judge/Sheriff/State Attorney), the Director of our Guidance Clinic, and CAHOOTS. We had over two hundred in attendance and still it is the topic of conversation around town.

Response 148:

Alone it is just one person against the world….
United we can move mountains
The Death of Hobo Joe

It's with a heavy heart and a sadness that I did not know existed in a human soul that I would like to share with you the passing of my son, Joseph. He was raised in Oceanside and in his adult years lived in the transient camps around Oceanside Blvd.. He was found Wednesday, October 6, 2021 in some bushes in Oceanside, CA. He was alone in the rain. Still wearing what appeared to be the hospital gown that he was wearing when he was dropped off by staff from the behavior health hospital on that previous Monday afternoon.

His death is a tragedy and could have been prevented if the doctors and social worker had truly listened to me when I begged them to not release him to the streets. I told them he was gonna die. His cause of death is under investigation by the San Diego Coroner.. An autopsy will be performed within the next few days. He just turned 30.

For those of you who do not know my son's story, it's not that much different than thousands and thousands of families out there. Joseph lived in transient camps in San Diego County with severe mental illness. We wanted him to live with us. In fact, we took early retirement to move him and us away from San Diego County 350 miles north to a small town in the foot of the Eastern Sierra mountain range. This area is where I was raised, and where we would take our children on vacations to visit my family. We felt that taking him to the mountains where he loved hiking and fishing, giving him a stress free life in the mountains and “loving him up” would "cure" him. I was delusional on that idea. Bishop did not have the level of care needed to treat his mental illness as well as his chronic medical problems. There is ONE County psychiatrist for the entire Inyo County, and she was trying desperately to retire.

His delusions had him convinced that living up here with us was endangering our lives. He was certain that if he did not leave and “surrender”, " they" would bomb our house, kill us, and put him in a cold dark room to die (not unlike the padded cell in jail where he would spend days at a time in, naked in a straight jacket). There were many nights I had to sleep in the bedroom with my adult son because he was terrified and convinced the SWAT Team had our house surrounded, bombs in hand. You see he was also was developmentally delayed and had an IQ of 70 on a good day.

He was continually being driven home by the Bishop PD because he would walk the two miles to their station and turn himself in.. He lived with us for only several months, and thinking he was saving our lives, he went back to the streets of Oceanside CA., in San Diego County. That was 3 years ago. Since that time his life had been a revolving door of mental hospitals, medical hospitals and jail. He has been hospitalized in behavioral health hospitals at least 9 times this last year. Sometimes against his will, oftentimes he would admit himself. On many occasions I would drive the 5 hour trip to pick him up, get a motel and would try to convince him to come home. He always refused. Stating our house would be bombed if he did.

I'm also angry...that's not even a strong enough word. Joe admitted himself last week to a Behavioral Health Hospital in Rancho Bernardo. That was his “go to” place. He liked the staff and doctors and they seemed to care about him. It was there 2 months ago that the psychiatrist determined he was unable to care for himself and referred him to the County Conservator’s office so his dad and I could gain control of his medical needs and help him obtain the long term help he needed. The conservitor investigator denied the claim because he did not meet the criteria of gravely disabled. In California the bar is set very high to meet the criteria of being gravely disabled. I have yet to know of anyone being successful with that endeavor in California. Accept Britney Spears. Her conservatorship is a slap in the face to those of us whose loved ones truly need help.
.
Last week Joey admitted himself because he was feeling suicidal and was psychotic. He would always call to tell me he was trying to get help. He wanted help so badly. On Friday, October 1st the social worker called. She was working on his discharge plan, and assured me that he would not be released to the streets. She was working on getting him reestablished with his care management team and finding him long-term housing, or into a temporary placement at a local Crisis Center. I stressed that he could not be released to the streets. She assured me he would not. Monday morning, October 4, the social worker called and said he was being released and would I pick him up? I asked what happened to the management team and housing? She explained that the care management team had not called her back and no one would accept him at the crisis centers because he had been violent with staff. I instantly asked her why she would ask me to pick him up if he had been violent? I begged her to have him put on as 5150 3-day involuntary hold, (because he was a danger to others) to buy me some time to figure out what to do, and also give me time to make arrangements to drive the 300 miles to pick him up, She said she was heading to a meeting about him and would talk to the doctors. I was clear when I stated to her that under no circumstances should he be released to the streets. I said, “ He is gonna die if we cannot get him the help he deserves” . She assured me they would not release him to the streets, and would get back to me later that afternoon.. She did not.

I called the hospital to talk with Joey that Monday night, he was no longer there. Still no call from the social worker. Tuesday morning I called the social worker at the hospital, yet again. She explained that her " team" had given my son a ride to Oceanside and dropped him off at a CVS pharmacy with his prescriptions and a sack lunch. I was in shock, hung up and waited for Joseph’s call. He always called.

His body was reported to the sheriff's office the next day, Tuesday night, October 5, 2021, but because of bad weather they could not locate him with drones. The homeless lady who reported him took them to his body Wednesday morning, October 6. He was still wearing what appeared to be his hospital gown and had a baggy of white powder clutched in his hand. He was steps from the homeless camp.

I'm so angry and devastated I want the system to pay for failing him. I want accountability. I'm so angry it's consumed me. I don't want to be consumed. In.my grief I called a wrongful death attorney and babbled like a banshee.. I told them I needed an attorney with enough balls to take on the "system" and make the "system" accountable for my son's death and the needless deaths of all the other Josephs out there. I want justice, awareness , accountability and the laws changed that bind the hands of families trying to get help to save their loved one’s lives . I promised my son his death will not have been in vain. The attorney politely said they will get back to me. I doubt it.

Meanwhile we sit here trying to figure out where we will come up with the money to bring our son home and have a memorial for him. Death is such a money making business. For a fee of $750 he can be cremated. For an extra $250 we can buy 30 minutes of time to see our son's dead body and tell him goodbye . ..That is if he is in viewable condition. After all, he had been left in the elements for over 24 hours and at the coroner for a week. He probably is beginning to smell and not looking too good. For an additional 800 they will make him viewable.

I want justice and accountability so no other family will ever have to receive the call that their mentally ill loved one has been found dead, in the rain, in the bushes , alone and afraid.

Response 149:

Hello,

I appreciate this chance to make input into this important topic.

My son suffers from serious mental illness. Fortunately, he is one of the lucky ones that (after spending 9 months in jail) was able to get treatment in Western State Hospital in Virginia, after being found NGrI (not guilty by reason of insanity)'

In my view, one of the most important parts of providing care is increasing the capacity of the state mental hospitals. Most do not have the beds/staff to handle the need. Too much money and focus goes to the jails/prisons and not enough resources are provided to the state hospital system. The insurance companies which set the rules for private hospitals, only allow minimum days of in-patient care (stabilize and release), leading to a revolving door of hospitalization, stabilization, release and decompensate. These conditions are chronic and many times need longer hospitalization and follow-up treatment. Usually, the medications themselves take at least 30 days to become effective.

One specific recommendation:End the IMD Exclusion,The IMD exclusion is a long-standing policy under Medicaid that prohibits the federal government from providing federal Medicaid funds to states for services rendered to certain Medicaid-eligible individuals who are patients in IMDs **(§1905(a)(30)(B)** of the Social Security Act [SSA]). When a Medicaid-eligible individual is a patient in an IMD, he or she cannot receive Medicaid coverage for services provided inside or outside the IMD. Due to the exceptions explained in the “Legislative History” section, the IMD exclusion applies to individuals aged 21 through 64.

This policy is clearly discriminatory! Needs to end NOW!

Thank you for your consideration.

Response 150:

Dear Chairman Wyden,

My son was diagnosed Schizophrenic at age 20. He is now 42 and in prison for attacking his father with a bread knife. He will be released 9/2023. He had Comcare
Services thru our county since he was diagnosed. He did not live with us, but we were always available for groceries., new clothes, rides to wherever, Cigarettes. We tried to guide him for many years. The year before the attack he was losing his SNAP card, bus pass, even his disability check. As possible programs would come up, I would encourage him to be involved and talk to his case manager about it. They never worked out, he didn't want attendant care because they wouldn't do what he wanted them to do. He refused to go to Breakthru club for socialization. He lost his section 8 housing because of his failure to self care. Case manager started telling us there was nothing they could do for him because he didn't want it or wouldn't cooperate.
He lived in a house and paid us very minimal rent but still couldn't take care of himself. At the time of the attack his case manager said she really thought he was not doing well.
He stabbed my husband 30 plus times, starting in his back. They fought and as David got weaker and weaker Jay would stand back and just watch him bleed. Every time David moved on the floor Jay would stan him again. Finally he left him to bleed out. I found him on the floor, bleeding to death. Dr.s said if he hadn't been in such good shape he would have died.
We tried for 17 years to help him and offered him guidance. But because of that State of Kansas would not give him a guardian. They said he had help and so many others didn't. He needed some kind of housing with Nursing available. Guidance so he would be fed , medicated, encouraged to be clean and sociable.
He had spend time in the State mental hospital over the years. First it was for 2 months each time he had a problem, later it was for 5 days because they were full. The local Psych hosp was always full of of the people with drug problems. Or depression. Or teen age problems so they couldn't take him either. The SMI are definitely short changed in Kansas. When he is released we will not be available to him, we have moved from the family home and he will not know where we are. He will literally be alone with no possessions. We emptied the house he lived in, (I should say shoveled it out) it has sold and only a few things of his are in my possession. The problem seems to be because he was an adult no one could force him to comply with guidelines.

At one point he was sent to Mental Health Court, except he only went once. I went several times just to see what was going on. The judge sent most clients to anger management classes. There were no consequences for him missingo courtn Idont know what will happen to him but we are 73 and 80 years old and deserve to have peace in our lives . Thank you

Response 151:

Dear Chairman Wyden,

Give families priority over their family member to get help for their mental illness when the patient will not comply with treatment plans need to establish mental facilities longer than a 7 to 10 days then release them an the whole process starts over. Need to establish at least a 90 day in the facility so patient can establish a routine that is not done in this 7 to 10 days then they are released when the patient is Un able to take meds or fend for themselves. Stop this nonsense so mental patients can get the help they need when they cannot have insight to much needed therapy that the way the stupid laws are now does not happen

Response 152:

Dear Chairman Wyden,

My daughter was a normal, intelligent, active girl until she reached puberty at the age of 12… that was when our whole family's life spiraled out of control. She is now almost 18 and it has not gotten easier. We have had 6 hospitalizations in the last 6 years. Three of those six had to be three hours away from home because there were no beds available locally. We have struggled to find the right meds and the right doctors.   We have gone into debt to pay for ambulances, medical bills, and weekly therapy. I teach Kindergarten and I have had to reach down into the depths of my soul to make it to work on days my daughter was facing challenges. It has bern rough on our entire family. My older son put off going away to school so he could be a support for our family, and my youngest daughter struggles with anxiety over her "crazy" sister. I know every family has its struggles, but the challenges we encountered in getting appropriate care for our daughter have been devastating and all consuming to say the least. My hope for other children and families struggling with mental health is that there will be a comprehensive approach to mental healthcare. A data base where communication between doctors is swift and the mysteries of what is happening in a child's brain can be addressed so that child can resume a more normal childhood.   Thank you for taking the time to read this.

Response 153:

Dear Chairman Wyden,

For 3 years I did not know my son's whereabouts. I filed a missing person's report finally after the first year. I wrote to the County Dept of Mental Health. I tried to hire a private investigator but lacked sufficient funds living as I was on Social Security Disability.
One afternoon I received a call from a woman who identified herself as a social worker. She asked whether or not I knew Travis Wilson.
I replied, "Of course. That's my son."

She then stated that he was in a hospital and that he had died 2 days prior. When he was admitted, he had not listed a next-of-kin so it had taken two days of research to locate a next of kin.
I then learned that he had been in something called SRO Housing in skid row. This was a program run by the County Department of Mental Health, the same mental health department that I had sent letters to asking whether or not my son was known to their system. . . with No Response.

Mind you I had filed a missing person's report with the L.A. County Sheriff's. My son was being housed and was receiving treatment from the L.A. County Department of Mental Health. According to the L.A. County Sheriff's Department, when there is an active case the HIPAA veil can be pierced. According to L.A.County Department of Mental Health Legal Counsel, the HIPAA veil could not be pierced.
The result was that I suffered severe anxiety and depression as the direct result of not knowing that my son was safe. I was not seeking to obtain his specific location. I simply wanted to know whether or not he was receiving care and had a roof over his head.
As much as I miss him since he has died, it is still far better for me than the "Not Knowing." The "Not Knowing" nearly killed me.

Response 154:

Dear Chairman Wyden,

Please adopt and fund all recommendations from Treatment Advocacy Center's letter regarding the bipartisan mental health care package.

Lack of medical care for serious mental illnesses is killing people, putting people in jail, and making people homeless.

You cannot have my story.

The injustices of your system are part of it. If you create a real healthcare system for people with serious mental illness, I will tell you my story.

Response 155:

Dear Chairman Wyden,

My name is Lisa Guzman and my son has Schizoaffecive disorder. Since the age of 20 years old. Evan has been treated in the Prison System of NYS for his SMI due to lack of funding since the age of 24. He has fallen through the cracks of this broken system many times. As recently as of April if this year while on a AOT. Assisted Outpatient Treatment Order. From April to July here in Rochester New York the Country of Monroe. Evan had a AOT that he was to go to mental health treatment, drug treatment and he did not comply. I would call his Intensive Case Manager, the head of AOT to no avail. I was told over and over there was nothing they could do. But according to the AOT order my son was a danger off his meds. On July 1st 2021 he was denied his injection of his Ability 300mg. For noncompliance of treatment. On July 5th he was arrested for allegedly murdering a man. This is what happens when the mental health services for SMI are substandard. This is what happens when services are cut. When parents are not allowed to be a part of adult children care. When you have Care Management who don't listen. When a AOT order is nothing but a piece of paper. Even though it is signed by a Judge. Once again my son has been failed by the very system that was supposed to help him. So many years ago when we started this journey I had so much hope but that is all gone now. Did I mention I work for The Office of Mental Health of New York? The U.S. Senate needs to make more money is put back in for SMI. For research,housing, drug treatment is big for them. No one seems to care about that. Stop cutting beds. The streets are full of homeless mentally ill people. I could go on but I will end it on this note. Stop the pipeline of sending mentally ill people to prison. Treat them were they can get the help they need. In a Psych hospital not prison. Trust me it doesn't work.

Response 156:

Dear Chairman Wyden,

All of Treatment Advocacy Center’s policy solutions would make significant life changing differences to; people with SMI, their families and society in many significant ways. Changes would save billions of public funds. Criminalization of SMI and improper treatment is inhumane and costing the public billions. Unacceptable how billions funds are spent on an ineffective system, when common sense changes would make significant improvements and decrease spending of public funds. Thank you for your help.

Response 157:

Dear Chairman Wyden,

I spent years trying to get help for my best friend with SMI, by the end of things, he was living on the street. It was heartbreaking to watch for many reasons, not least of all the fact that it was so unnecessary, so unavoidable. If there had just been programs in place to get him help, get him safe, a lot of people could've been spared a lot of suffering and pain. It's not just the life of the person suffering SMI affected, it's all the lives around them. Please, help our most vulnerable members of society get the help they need and deserve.

Response 158:

Dear Chairman Wyden,

The barriers to prompt medical treatment for our adult child with a treatable no fault brain disease resulted in 8 years of untreated psychosis and decompensation, homelessness, sitting in a jail cell for over a year with no medication or treatment, being allowed to defend himself in a state of psychosis for a nonviolent crime that resulted from his untreated brain disease, then retroactively being put in diversion court and having his record expunged. Our state and country, by allowing these organ based diseases to be treated by the judicial system and not doctors, and by not integrating our healthcare systems, are actively damaging peoples' brains and their chance

at a productive, humane life. If this was any other organ based disease, such as cardiac, Alzheimer's or diabetes, we would not think of blocking people from care or ejecting people prematurely from hospitals where they are recieving life saving medical care. 50% of people living with schizophrenia suffer from the symptom of anosognosia, or lack of awareness they are sick--the biggest impediment to seeking voluntary care. We need to recognize this and lower our country's standards for compassionate involuntary care. Hospital doctors provide life saving care all the time for people who have lost their decision making capacity due to stroke and other medical conditions. We need to do the same for those suffering from psychosis, likened to a slow moving stroke. Time until treatment = brain deterioration. Until we understand these illnesses for what they are, medical neurological brain diseases, and stop treating them as "behavioral" or "mind" disorders not much will change from our sickest with schizophrenia (one of the most debilitating diseases), bipolar and other psychosis spectrum diseases.
To improve our system we need to:
-Repeal the discriminatory harmful IMD exclusion that has choked the supply of treatment beds and stifled an adequate continuum of care -Repeal the Medicare 190 day lifetime limit-these illnesses are chronic, lifetime diseases and need longer stays to stabilize patients, and repeal the the limit of 15 days per month in an inpatient psychiatric hospital bed -Incorporate HR 2611 into your final legislative product -Expand federal funding for Assisted Outpatient Treatment (AOT) programs, one of the few alternatives left to families to get their loved one who cannot be medication compliant into supported treatment -Provide funding for healing supportive housing that people need going back into their communities
https://hth.ttinet.com/Housing_That_Heals_2020.pdf
-Make telehealth, with the provision of mandated in-person periodic in person visits with doctors, permanent -Require the CDC, in partnership with the NIMH, to conduct an independent surveillance study establishing credible epidemiological current estimates for the number of people in our country living with schizophrenia

Thank you for your consideration. It is long past time to equalize medical care recognizing the whole person. Let's stop this artificial bifurcation of brain health and all other health and stop the humanitarian crisis of our homeless and jailed people whose only "crime" is having a treatable medical brain disease. "What you ignore, you empower."

Response 159:

Dear Chairman Wyden,

My brother diagnosed with paranoid schizophrenia at age 19 and lived his life in the family home. during one of his hospitalizations a social worker connected him with the Seward Dropi In center in Minneapolis for persons with SMI. His hospitalizations for psychiatric decompensations decreased. Two things that made all the difference for my brother: stable housing and community mental bealth.center.

Response 160:

I wish my son was doing was Eric Smith at Treatment Advocacy Center is doing, but their trajectories with severe and similar mental illnesses had one huge difference. Eric had access to

Assisted Outpatient Treatment. Eric now advocates for AOT to expand nationwide and uses the story of how AOT "saved his life." My son, on the other hand, didn't get AOT. Lack of AOT killed my son. He died of suicide in a state of psychosis, desperately ill and long past a point where a responsible care team could have lifted him toward meaningful recovery. Our state involuntarily hospitalized and incarcerated him multiple times, discharging him onto the streets without a supportive team or any coherent follow through. He needed AOT. With an infusion of federal dollars, AOT can be the scaffolding to create whole-person care that includes a team approach, with motivational support from a caring judge, linkages to housing and vocational support, and community engagement. With AOT, a person's outcomes can become stable housing, restored relationships, meaningful work... instead of homelessness, destitution, incarceration, and death from suicide, all of which became the result of poor care for my son. Fund AOT.

Response 161:

Dear Chairman Wyden,

i would encourage you to consider the recommendations by the Treatment Advocacy Center. My Mother was mentally ill her her life. She needed medication and support--most noticibly a psych hospital bed.

Response 162:

Dear Chairman Wyden,

My son Stepehn is serving life without parole for running over 17 people , killing 3, on the Las Vegas Strip i September 2005. In the 2 years prior to this, Stephen began to exhibit behavior that eventually led to a diagnosis of bipolar disorder, then paranoid schizophrenia. He used alcohol and drugs which made him worse. He was in and out of a private rehabilitation facility, and in and out of jail. The jail released him to the County hospital for 72 hour evaluation, but he was sent home to us within 3 hours. He beat me unconscious, stole my car, and drove from Southern California to Las Vegas, then in the middle of a psychotic episode, ran the people down. We were unable to get Stephen the help he needed because he was 27 at the time. Although he had been sentenced as guilty but mentally ill, he was not given treatment nor medication until Treatment Advocacy Center helped us navigate treatment. Once he was properly diagnosed and treated with proper medication, he improved greatly and is now stable and doing ok in isolation in prison. Treatment Advocacy understood the issues and are an excellent resource I wish I had known about before our tragedy. Including emergency responders with knowledge and experience with mental illness, and facilities to provide proper diagnosis and treatment and housing with mental health care would have been valuable resources had they been available.Please do everything you possibly can to get first responders trained to work with mental illness and have places to send these suffering people in desperate need of help. Lives depend on your decisions and you can make a great difference moving forward. Thank you.

Response 163:

Dear Chairman Wyden,

I support all the Treatment Advocacy Center's recommendations and am especially highlighting this one that is near and dear to our family hearts: Fund programs that are tailored to community resources and divert people with SMI away from criminal justice involvement to the greatest extent possible. In the throes of psychosis and high on drugs, our son burglarized our home, thinking it wasn't a real crime. He was turned away from Mental Health Court because he lived in a different county than we do, so went to district court, charged with a felony. Unacceptable! He needed medical care, not jail.

Response 164:

Dear Chairman Wyden,

My brother has struggled with schizophrenia for 30 years. His situation has devolved into countless emergency room visits, voluntary and involuntary psychiatric commitments, and years of sleeping outdoors or in his own filth. He is finally receiving supervised care-- two months so far in the county jail for a failure to appear at his court date after breaking into the local homeless center on a cold and rainy night. If Aaron had real access to the community resources described by our state's legislature on paper, coupled with a judicial framework (A.O.T. / Mental Health Court) to help him overcome his delusion of health, many taxpayer dollars and communal heartbreak could have been saved.

Response 165:

Dear Chairman Wyden,

Dear Senate Committee on Finance,
Please, I urge you to consider all of these suggestions put forth by The Treatment Advocacy Center, as these are all common sense measures that will assist persons with severe mental illness in gaining meaningful access to treatment and in maintaining compliance with treatment. These measures will improve the lives of persons struggling with mental illness, reduce stress and turmoil on their family members, and improve the safety of the public. These measures will also save tax payers money, by helping persons with mental illness avoid incarceration. It will be a win-win solution for all.

Response 166:

Dear Chairman Wyden,

I have been a member of an advisory board for an accredited Clubhouse for over twenty years. Clubhouses change the lives of those living with mental illness as well as their communities. Through employment, socialization, recreation, and education, members can see their way out of long-term isolation, chronic hospitalization, and criminal justice systems. Funding it and other community programs such as ACT and First Episode Psychosis will make a huge difference in our efforts to create a healthier, happier, and more prosperous America.

Response 167:

Dear Chairman Wyden,

My mother was diagnosed with Bipolar Disorder 40 years ago, and with hundreds of ER visits that did not lead to any follow-up care that was feasible, and her reliance solely on Medicare for her treatment, the Repeal the Medicare-190 day lifetime limit section of this proposal could perhaps allow her to remain stable in her final years. As of now, her insurance covers very little towards mental health, and her symptoms are somatic- which has led to her being given pain medication, which is addicting and offers little in decreasing the symptoms. Please consider this proposal and support the changes that need to be made.

Response 168:

Dear Chairman Wyden,

My son, age 32, lives with schizoaffective disorder, bipolar type. This disease has the ups and downs of bipolar, along with the psychosis of schizophrenia. He was a bright student and athlete growing up, and a senior at UC Santa Barbara when first diagnosed at age 21. Since then, he has been hospitalized 20 times and was placed under county conservatorship in 2017. Conservatorship is the only way he was able to get the long term care he needed, and we were lucky to get it. There are few private facilities that will accept patients with his critical needs, and their cost is exorbitant.

Because his father passed away in 2014, he had Medicare insurance in addition to private insurance. He ran through the Medicare 190 day lifetime maximum long term hospital stay quickly, and private insurance did not cover his lengthy hospitalizations, so I was forced to drop private insurance in order to get him conserved. He has moved locations several times, and the social workers are constantly working to find him a bed, as there is such a shortage. My hope is that you will address the mental health issues advocated by Treatment Advocacy Center, which especially address the needs of the seriously mentally ill population.

Thank you for your attention.

Response 169:

Dear Chairman Wyden,

I am the Executive Director of a public safety net behavioral health in Louisiana. Medicaid rates for services are atrocious and many of the people most in need, due to the impacts on their lives of these behavioral health conditions, are on Medicaid. This results in a scarcity of adequate services for them. As with any health condition, improper management of a health condition typically leads to a worsened condition. Worsened conditions lead to poor outcomes and increased costs to the system for hospitalizations and other higher level services. The single most effective thing that could improve outcomes would be appropriate reimbursement.

Further, other things that could positively impact outcomes, in terms of health and financially, would be housing supports and reimbursement for case management. Both of these issues have been shown to improve outcomes and saving money by not paying for those services continues to cost more and more over time as poor outcomes lead to increased costs, not to mention the impacts it has on individual and family health and well being.

Thank you for your attention to such an important issue. I look forward to positive changes and would be happy to assist in any way I can from my level.

Response 170:

Dear Chairman Wyden,

As a parent of a young adult with SMI (with many hardships to prove it) as well as a member of NAMI and supporter of the Treatment Advocacy Center, the single biggest problem we have in this country is not acknowledging that Brain Disorders are Physical Diseases - and need to be treated as such. This means more beds in both private and psychiatric hospitals, more AOT, more Doctors (that take insurance) , more clinicians that take insurance, more money directed to research and so much more. The mental health system in this country is absolutely broken and families are falling apart as a result. Also - as a parent with a child diagnosed as schizophrenic - I can tell you that the NIMH data on the prevalence of this disease is WAY undercounted.

Response 171:

Dear Chairman Wyden,

My story is professional and personal. I am both a licensed attorney, and an ordained and endorsed denominational pastor and hospital and hospice chaplain. As an attorney doing appointed counsel work, the phrase "criminalization of the mentally ill" was something that I saw regularly. Treating those with mental illness by criminal standards makes as much sense as treating medical issues as criminal issues when it is nothing more than misunderstanding medical treatment issues and medical delivery issues. We don't criminalize the physically ill, but we do criminalize the mentally ill because there are no good support structures for them. It is wrong and unjust to have a lack of community policy regarding mental health because it leaves the most vulnerable with no place to be cared for but the criminal justice system. Mental health policy is health care, and it needs to come under community social services. As a pastor and a chaplain, I cannot tell you the heartbreaking things I have had to witness, when the medical institutions I have worked at have had to send homeless cancer patients back to living in public parks, or visiting hospice patients living in tents, on public or private properties. Once can be both mentally ill and physically sick. 90% of what is wrong with our nation currently is related to mental health: homelessness, which is heavily related to mental illness, PTSD, and drug use as a form of self-medication. Widespread addictions have mental health components and may have mental illness components. Indiscriminate gun use nearly always has a mental health or mental illness component. The vast majority of police interactions, including those that go awry are mental health or mental illness related. Why not simply put the money into community mental health facilities, and treat all the things I have named above before they become homeless, before they become ill and homeless, before they become violent and homeless, and before they become entangled with the law and criminal justice system unnecessarily? I hope you will follow the recommendations set forth by the Treatment Advocacy Center. We need to start taking steps in the right directions.

Response 172:

Dear Chairman Wyden,

My daughter has schizophrenia, bipolar and severe anxiety disorder. Her mental health issues have ruined her life and now define her as she has been sentenced to 27 years in prison for actions she took while delusional. This was all covered by the national news.And much of it was reported incorrectly my daughter look like monster, not some one with long-standing mental illness.
In Iowa, we house people in prisons, instead of fixing our woefully broken MI health care systems.
I don't have all the answers, but providing treatment facilities would be a start. We desperately need MI beds AND professionals! My daughter had more than 200 encounters with the existing system, to no avail. And many, many encounters with the police. Although our city has a crisis response team, our police never used them when I would call during critical episodes with my daughter.I don't know what the daily cost of keeping a person with MI in prison, but I am sure it is far more than treating a person. And much more humanly.
All of the purposed solutions look good. Not sure how to pick one that would have the most and best impact.

Response 173:

Dear Chairman Wyden,

Why is this common-sense action so hard to pass? I could give you many a story of the major problems for those with mental illness and their families but instead hope that you follow common sense and read the Treatment Advcocacy Center recommendations as well as the similar recommendations of other non-profit agencies like NAMI who are on the front lines of mental illness every day.

Response 174:

NAMI Urban LA: NAMI Urban LA involuntary mental health program in Los Angeles which is referred to as NAMI Urban LA, LPS Conservatorship Program. The purpose of the LPS program is to educate and help families navigate an extremely complex system so they will be able to help their love one acquire mental health treatment necessary for their recovery. The present system is wrought with loopholes and legislation that withholds mental health treatment as well as preventing mental health treatment. The results of the inadequacy of the convoluted mental health system is noted by the abundance of homelessness, incarcerations, and hospitalizations.

Serious mental illness (SMI) is a life long illness just as is dementia, Alzheimer, autism and other brain affected illnesses. Greater than sixty percent of the people affected with SMI lose their ability to recognize their illness and therefore refuse treatment and medication and are non-compliant with treatment. Untreated mental illness is dangerous as no one has the ability to know what a person's mind is telling them. These are the people we see repeatedly in the hospitals, jails, and streets.

Unless you walk the road with someone who has a serious mental illness, you really do not understand the seriousness of the situation. This includes psychiatrists, psychologist, attorneys, legislators and social workers who lack the capacity to really understand SMI.

The present practice prior to acquiring treatment requires the person to exhibit repeated hospitalizations, incarcerations or homelessness for years (10-20 years) before the necessary involuntary treatment is mandated. When mandated treatment is granted, few resources are available for treatment as funding has gone to those with mental health problems, not those with serious mental illness. Meanwhile the person's brain has deteriorated significantly and will need exceptionally longer treatment.

I have walked the road seeking treatment for my son whose diagnosis was schizophrenia. For the sake of privacy I will refer to my son as Joe. Joe was a brilliant mathematician graduating from Louisiana State University. While studying at the university, he began to develop this horrendous illness. Generally young men develop mental illness in their late teens early twenties and girls in the mid to late twenties. No one called us to state there was a problem due to the isolating HIPAA rules . Joe was so ill that anyone could recognize he had a problem. Joe did not have the mental ability to acknowledge or seek treatment for his deteriorating brain.

Joe did manage to graduate in May 2002 and somehow ended up in California along the west coast. By this time, Joe could barely speak and definitely was not in touch with reality. The main part of Joe's brain did work. It was the frontal lobe that was not able to process information and needed treatment.

Our loving, brilliant, funny and delightful son was lost and was extremely ill. We would receive collect phone calls (pay phones were in existence at the time) with three words from him, "I need help." Click, he would hang up. It would be days and sometimes weeks before we would hear from him again. We could trace his calls throughout California as he was able to travel from the north to the south.

Christmas Eve, we booked the last available airline ticket for Christmas Day which left Louisiana in the morning and flew to California. I rented a car and drove to Santa Ana to scout the area just hoping we would receive another call and maybe I could find him. I picked up a young homeless man who showed me the ropes of the street. Of course, this fellow was an empty well and needed nourishment to keep him going. My Christmas miracle was finding our son Christmas evening. Joe had no idea who I was when he saw me. He was afraid of me. The homeless man went over to talk with Joe. As I watched them together, it was like a light switch went on, instantly, Joe's facial features changed and he recognized me. He was able to speak in short sentences and wanted to go with me to his grandmother's house in Los Angeles.

The next day, again Joe could no longer talk. He sat and stared for hours without blinking. A neighbor who was a psychologist said he was suffering from attachment syndrome and that I, his mother, caused this problem to develop. I knew these statements were not true.

I called everyone, psychiatrists, 911, Department of Mental Health (DMH) and received absolutely no help. I was told Joe needed to call and ask for help. I said he could not even make a phone call let alone talk enough to ask for help. I was suggested I, "put him in the hospital." But to get him in the hospital, he needed SSI. To get SSI, he needed to be in the hospital. How do I break into this system. In those days, once you graduate from college, you no longer have insurance.

I was sure Joe's problem was drugs and alcohol. But for a week Joe did not have any substance. What could he have taken that causes this inability to talk and communicate? I new nothing about mental illness, so in my mind the problem had to be substance abuse.

Ringing in the New Year was to be spent in an AA meeting. On the way to the meeting, Joe ceased to function. He became limp. His hand was cold and clammy. Immediately I drove to Cedar Sinai, the nearest hospital. A gurney was brought to the car as Joe's body was like a rag doll. All Joe could do was blow bubbles with his mouth and flutter his eyes. Six hours he was in this catatonic state in the ER. As his mother, I just asked God to let him live. I had no idea what was wrong. The treating doctor said there was nothing wrong with him, that Joe could hear him. The doctor ran ammonia up Joe's nose burning his nose and mouth. This brought him slightly out of the catatonic state. So Joe was discharged from the ER. Only to return the next evening with the same situation and to be released again with no treatment nor diagnosis.

February 3, 2003, Joe proceeded to beat me up. While hitting me, he calmly asked, "Why are you screaming?" By this time, Joe was only 135 pounds so I could utilize my karate training and push him back without hurting him. Joe had no idea what he was doing nor would he have any memory of this incident.

Twilight zone was now my reality. As the police arrived to take Joe to jail, the ambulance to take me to the hospital, an UPS truck arrived to deliver a surf board, wet suit and four math books. Apparently Joe was able to see the numbers on a charge card I had, and order on the computer these items. As I said, his brain works and numbers were his specialty. Even though Joe's frontal lobe for reality was mal-functioning, he was able to accomplish ordering these items.

It took fifteen years for Joe to acquire treatment for the level of care he needed for recovery. During this time his brilliant brain continued to deteriorate. Why did Joe not receive treatment earlier? It was not because of the lack of his family trying to help him but because of a system that is designed to withhold and prevent treatment. All research depicts the value of early treatment. But the laws demand that a person become so ill that they cannot provide for their food, clothing or shelter before treatment is given. Because resources for treatment of those with serious mental illness is so scarce, hospitals continue to discharge very ill patients. Hospitals are not liable when they discharge a person with a mental illness. It does not matter how ill the person is, or even if the person should leave the hospital and lay on a railroad track within hours of discharge and die, the hospital and doctor are not liable.

Our children are and will always be our children no matter their age. No law can change the love we have for our children and when they need help for any illness. As parents we try to meet their needs. We are our brothers' keepers. Too many brilliant and talented people are abandoned by their family because living with a person with SMI is not possible, especially when you have to fight a system that wastes money and time continuing to withhold treatment for those with SMI. This is discrimination at it's best. No illness has laws preventing and encouraging a lack of treatment. No person should have to experience this horrendous illness for 10 to 20 years before they are able to receive treatment for their recovery. Would you want this for yourself, should you become ill, or for your children?

On a good note, after treatment, Joe is going on his third year of a happy marriage, seeking quality employment, and helping other families fight a system to gain treatment for the recovery of their child.

Common sense is needed to fix this mental and inadequate system of ineptness. These should be federal laws.

1. Change HIPAA laws to require a responsible person be granted knowledge for treatment for a person with mental illness. Make this the law of the land.
2. Make mental health federal laws to cover treatment for those with SMI as these people tend to cross state lines and are resourceful enough to travel, but lack the ability to seek help. Treatment is withheld if they are not in the areas of their "residency."
3. Create a "Green Alert" for those with SMI who are missing just as we do for children. Age should not be taken into account when the brain ceases to function.
4. A family seeking a SMI missing person should be told by the police where the person is located. The police should have the ability to hold the person if necessary.
5. Provide funding and demand quality treatment facilities for those with SMI. Require oversight and accountability.
6. Change laws to provide prompt evaluations and treatment for the level of care necessary for recovery for those with SMI, regardless of the person's age.
7. Hold doctors, hospitals, and insurance companies accountable when they withhold treatment for the level of care necessary for a person's recovery.
8. Provide a national medical directive specifically for those with SMI or mental illness.
9. Change the bar for treatment. Delete "gravely disabled" and add that two doctors, and if necessary, a third doctor's opinion is required to be the standard to proceed with involuntary mental health treatment. Allow the patient to request a court evaluation should the patient disagree with the doctor's opinion. Courts should not be automatic in the process unless the patient requests the court's opinion.
10. Increase funding, proportional to the population, for research on schizophrenia, bipolar and schizoid-affective disorder to seek a cure. More money is spent on AIDs per person

> than mental illness which is an illness that is not preventable. Too many brilliant minds are lost to these illnesses.

Response 175:

Dear Senators Wyden and Crapo,

I was very appreciative of your 21 Sept. letter regarding the need for expansion of access to mental health services in our country and I thought the following article may be of interest to you in this context: https://www.smerconish.com/exclusive-content/why-biden-needs-to-appoint-a-psychological-advisor. I would be glad to speak with you further about this idea at your earliest convenience.

Response 176:

Dear Chairman Wyden and Ranking Member Crapo:

We are so grateful that the U.S. Senate Committee on Finance is gathering information to develop a bipartisan legislative package to address behavioral health care challenges faced by millions of Americans. We are respectfully submitting some recommendations for consideration (attached).

As background, earlier this year, we were asked by the U.S. Congressional Hispanic Caucus (CHC) to meet to discuss recommendations on mental health policies for Hispanics in this pandemic recovery period, given mental health disparities have widened on existing inequities. The CHC then asked us to develop a report of recommendations for Hispanic/Latinx community mental health.

We responded to this request with a document focused on promoting mental health equity for Hispanic Americans for the US Congressional Mental Health Caucus and the US Congressional Hispanic Caucus. This document addresses many of the priority areas listed in your request (see attached). It was prepared in partnership with over 30 science and policy experts across academia (Columbia University, Duke University, Harvard University, Stanford University, University of California Davis, University of California San Francisco, Washington University, Yale University), foundations (California Health Care Foundation, Hogg Foundation), hospitals (Massachusetts General Hospital, Zuckerberg San Francisco General Hospital), and public health agencies (San Francisco Department of Public Health, New York State Office of Mental Health). In addition, four past American Psychiatric Association Presidents reviewed and approved this work.

If you have any questions, please feel free to reach out.

Response 177:

Dear Chairman Wyden,

My young adult son is in jail because he is mentally ill. He had to be arrested in order to send him to a psychiatric facility against his will. Unfortunately, the psychiatric facility sent him to a hospital to have them see him about a medical issue - they then took it upon themselves to do a psych evaluation for suicide (which is not what was needed), and the hospital then turned him loose instead of sending him back to the facility for the psych evaluation and treatment that was needed! The police then had no choice but to arrest him and take him to jail which is where he sits because he is refusing the PTI diversion program which would help him get out of this situation. Instead, he wants to go to trial; that alone proves he is psychotic and delusional. Our health care system has been screwed up since all the mental institutions were closed. The majority of homeless are veterans and mentally ill. A good portion of those in our jails and prisons are mentally ill. We need new hospitals and institutions for the mentally ill that are filled with compassionate caretakers and then once they are stable, they can either go home to family members that can take care of them OR they need to go to group homes also with caretakers who will help them; i.e., remind them to take their medications, help them to find jobs and learn to be self-sufficient. And, if they need to live with people like that in a group home for the rest of their lives - so be it. But right now, the system is BROKEN and somebody needs to fix it...

Response 178:

Dear Chairman Wyden,

Assisted Outpatient Treatment is an essential component of enabling many people with serious mental illness -- particularly psychotic disorders such as schizophrenia and bipolar disorder to function safely and reasonably in the community. About 40-50% of people with these conditions have something called 'anosognosia, which is a BRAIN CONDITION that compromises ANY INSIGHT into their having an illness. This subgroup is consequently most often homeless, engaged in activity that results in criminal justice involvement and spiraling dysfunction together with escalating costs. AOT is an important set of interventions for THIS subgroup. it is THE humane approach to enabling people to live in the community. We have a fmaily member -- formerly high functioning administrator in a national scientific area who HAS this condition as a aprt of his bipolar illness -- and as many in this group, he has spun into psychosis, homelessness and multiple interaction with law enforcement while refusing any kind of treatment. it is simply tragic and avoidable. I am speaking as a public psychiatrist myself who has served in very senior level public policy and executive positions -- and I have born witness to the unraveling of our safety net without AOT capacity becoming a reality. I cannot support this approach enough.

Response 179:

Dear Chairman Wyden,

I am writing to endorse all of the recommendations of the Treatment Advocacy Center. In addition, we need to address the chronic homelessness of these Individuals, and put more funding into research for new treatments, and prevention.

Response 180:

Dear Chairman Wyden,

My son was killed (allowed to die with no treatment or intervention) in a state psychiatric hospital in New Jersey.

He was on a medicine known to reduce appetite. He refused food. They did nothing about it in 30 days!!!!! They did not nourish him, nor give him water. They did not give him any medical attention. He died at the nearby medical hospital less than 24 hours after admission, when his organs failed and his heart gave out.

All of this was due to my not knowing ANYTHING about his condition because he did not sign the HIPAA papers because he was in psychosis for the entire 2 months in this institution.

We must remove the barrier to correct treatment by removing the need for a psychotic patient to give consent.

He was 29 years old and a brilliant artist. It was a life snuffed out!

Response 181:

Dear Chairman Wyden,

Please help families who have taken their severely mentally I'll loved ones to the hospital only to find that there are no longer any long term care facilities for incurable insanity. The families are in danger, as is the community and the sick individual. There must be clear and simple referrals available in all Anerican hospitals so that these people are not turned away. SuRely our medical schools and hospitals can reinstitute the asylums of the past, or if not, some easily accessible group home system with psychiatric care for these tortured citizens. Our family has repeatedly had to rescue our lived one from homeless shelters and jails, where they were being held for vagrancy. A psychotic patient needs round the clock care, which a family can't provide in most serious cases. The naive experiment allowing the asylums to disgorge their patients to the streets in favor of allowing patients to seek their own treatment voluntarily has proved to be a total failure and must be addressed. Lives depend on this!

Response 182:

Dear Chairman Wyden,

HIPAA wording changes to encourage and support teamwork among a person with SMI, their providers, and their family would help community programs improve outcomes and thus reduce the need for emergency and justice involvement.

Response 183:

Dear Chairman Wyden,

My 28 year old son has suffered from an untreated mental illness for 9 years. He has had 3 involuntary hospitalizations. Due to the Hippa Law I have been repeatedly left out of his treatment plan. A plan he never follows upon discharge. He has dense anosognosia and will not comply with treatment. He is caught in a revolving cycle leading to a life of despair and emptiness. Hippa Laws have to be repealed to allow the family of SMI loved ones to be an integral part of their treatment.

Response 184:

Dear Chairman Wyden,

Hi, and thanks for your work on making changes to a mental health system that is severely broken and misguided.

I am the mother of a 39-year-old man with paranoid schizophrenia. He began to show symptoms at the age of 15, after a bright and happy childhood - and while his life fell apart, no one was able to help. He was finally diagnosed at age 19 - and have had 9 hospitalizations since.

Without family support, I am certain my son would be in jail. He is not violent, but his delusions do lead him to very odd behaviors that scare some people.

In treatment (currently a long-acting injectable), he becomes stable, even employable. He still struggles, especially because his illness comes with a symptom (anosognosia) that prevents him from realizing he is ill. The misguided "right" to refuse treatment has, in the past, led to job loss, homelessness, shoplifting, arrests, and involuntary commitment. He has also, in his stupors, been a frequent victim of crime as well.

There were times he was refused a hospital bed because there simply weren't any available. At those times, he frightened all of us with his behaviors - including his young nieces and nephew.

With enforced treatment, housing, and opportunities, he can have a semblance of a normal life. So much has been taken from him by this illness - his ambition, his joy, his sanity. He deserves support and help.

I support:
Fund programs that are tailored to community resources and divert people with SMI away from criminal justice involvement to the greatest extent possible⍰Include emergency responders with knowledge and experience with SMI—including but not limited to schizophrenia, bipolar disorder, major depression, and other

Response 185:

Good morning,

I am the Executive Director of the Family Healthcare Foundation. The Family Healthcare Foundation is a Tampa Bay nonprofit that promotes equitable access to healthcare for individuals, children, and families through application assistance for public health programs (CHIP, ACA, etc), outreach, and coalition building.

I am submitting public comment on behalf of the Family Healthcare Foundation in response to the request for comments published on September 21, 2021.

- In regards to the shortages of providers specializing in children's behavioral health care, we recognize Pediatric Specialities are severely understaffed. Incentivizing new providers such as expanding the National Health Service Corps student loan forgiveness program eligibility criteria to include metropolitan and non-rural designated areas may incentivize those considering a career as pediatric mental health and behavioral health providers.
- In regards to non-clinical professional recommendations, Healthcare Navigators and community health workers are a powerful workforce that have the opportunity to provide on-going medical case management services to connect children to care. Through the Family Health Care Foundation's Connecting Children to CARE program, funded by the Children's Board of Hillsborough County, we assist families with healthcare program applications (Medicaid, CHIP, ACA, etc), and then follow a subset of those children to assist them with making appointments and reminders to attend well-child visits. This program had a 91% success rate during our last evaluation period for compliance with attending visits (2020-2021). Identifying specialists, troubleshooting insurance complications, and scheduling appointments have been some of the top barriers that the Healthcare Navigators have assisted families overcome. Expanding support to non-clinical professionals to ensure access to healthcare is vital to medical care utilization. In addition, expanding school-based psychological services may have prevent crisis behavioral health occurrences, and provide behavioral health needs in the locations where children spend much of their time.
- Care integration for children in the State of Florida is uniquely siloed for CHIP recipients. Streamlining CHIP to be handled by one state agency (instead of four) could result in faster eligibility determination, and potentially faster reimbursement of providers.

Thank you for reviewing these comments.

Response 186:

Dear Finance Committee:

I think the most effective legislative change would be to require states to make Medicaid reimbursement or funding available for the support of Soteria houses and Peer-run Respite Houses. These are two alternatives to the conventional treatment for people diagnosed with severe mental illness. Soteria houses and Peer-run Respite houses are much more effective than the conventional treatment. Soteria houses report 60 percent of patients reaching full recovery from psychosis. Peer Respite houses are important sanctuaries for people who are going through psychiatric crises. I am a clinical psychologist in Las Cruces, New Mexico and a Past Executive Director of the International Society for Ethical Psychology and Psychiatry.

Response 187:

To the United States Senate Committee on Finance:

With gratitude for your interest, I am responding briefly to your September 21, 2021 request for proposals on this topic.

First, a tiny introduction. After discharge from military service, and then a great deal of training in how to do therapy, I began full-time counseling and psychotherapy employment in 1975 in Tucson, AZ in a program for people addicted to heroin and wishing to detoxify. My annual full-time salary was $7000.

Ten years later, having started a private practice and now paying my own overhead costs, I was receiving $60 an hour from health insurers to treat all manner of clients in an outpatient setting for the same issues. Thirty years later when I discontinued my relationship with insurance companies, they were still reimbursing at the rate of $60 an hour. The laws of inflation meant I was receiving now $30 an hour in actual purchasing value.

The longest and largest factor creating ‘gaps in care’ has been health insurance companies’ consistent, blatant monopoly on reimbursement rates and ’managed care,’ setting specific limitations on treatment length and limiting treatment models to short-term methods that do not demonstrate real results for clients over time. Their model of “in-network” therapists — the only providers they reimburse — vastly constricts which providers their members can see and how many will be seen.

The policy solution I suggest would be federal mandates for insurance reimbursement rates, increased every year re: an inflation index, and federal respect (and cross-state acceptance) for State licensing standards for those MD, PhD, MSW, and LPC credentials. No insurance company would be immune from these mandates, and there would be one, and only one portal for billing and reimbursement to therapists, with a ten-business day turnaround.

For those citizens without insurance, a federal program would exist to offer The Same coverage to all citizens that qualified by means-testing. Insurance “networks or panels” of approved-therapists would be abolished. Federal laws (much like income tax laws) would assess industry compliance, year after year. The hourly fees paid by insurance companies would now begin at a much increased rate, using for instance 1975 and $60 as a base, with inflation now factored back in over 46 years.

This would encourage greater health care provider participation and vastly greater participation by citizens needing care.

Having many many observations now in my 46 years of practice, I could go on and on. The scope of your letter is remarkable to me, since many of us have been singing in the dark about all this for decades. I have lots of thoughts, but I confess I do not have confidence in a federal consensus forming, and funding for the long term, this evolution and modernization of mental health care in America.

Please contact me if I can be of any assistance. My website below offers some indications of my training and interest.

Response 188:

Dear Chairman Wyden,

We are a Washington state family (King County Metro area) with a young adult daughter who has a dual diagnosis of intellectual disability and severe mental illness.

We have much experience with both inpatient and outpatient services, voluntary and involuntary.

I wholeheartedly concur with the list of solutions submitted by the Treatment Advocacy Center. AND, I would add that the prevalence rate for people with I/DD and mental illness is estimated at about 40% and yet mental health services for this population are practically non-existent (at least in our state). This is a specialized, highly vulnerable population that often doesn't even come up in mental health reform discussions. They can suffer with inadequate treatment options. Their families can suffer as they try to keep them and the family safe and healthy.

I encourage you to seek input from NADD to understand the needs and reasons for lack of representation in the mental health care systems.

Thank you for focusing on this critical issue for our country.

Response 189:

Dear Chairman Wyden,

My name is Dr. Christine M. Sarteschi. I am a Professor of Social Work and Criminology at Chatham University in Pittsburgh, Pennsylvania. I have spent much of my adult life, as both a clinician and a researcher, working with individuals and families who have been burdened by the poorly functioning mental health system. Extremely limited psychiatric hospital bed capacity has left many without necessary treatment. One consequence of this reality is that many individuals with serious mental illness are now interacting with law enforcement. Law enforcement professionals are not mental health practitioners, yet they have become the first responders to many of the mental health crises in the United States.

Lack of mental health training is a major shortcoming of law enforcement in the United States. Mental health training is often absent in the police academy curriculum and when it is included, its presence is very minimal. In many police departments, across the country, Crisis Intervention

Team (CIT) training is offered but not mandated. It is purely optional in most training programs. Instead, it should be mandated that all officers have a working knowledge of the appropriate method for interaction with the mentally ill.

In my experience, officers who have received mental health training, behave in a qualitatively different way, than those who have not received such training. As a clinician, I have had to assist families in notifying the police in emergency situations. In many instances, it was only the police who were legally able to transport a mentally ill individual to the hospital. The clients were obviously ill and needed immediate medical care, yet the only option available was to call the police. The clients were usually meek, confused, often elderly, and posed no danger, yet they were handcuffed, leg cuffed, put into a police vehicle, and then driven to a hospital. It was difficult to explain to frightened clients and their families, why they were being treated like criminals. Especially, in light of the fact that their destination was not the local police station but was instead the local hospital. It was a frightening experience for my clients and their families, and one that seems unnecessarily traumatic for individuals requiring medical care.

In my experience, when the police arrived at the scene, it was evident and later confirmed, which officers had received mental health training. The officers who had received training often expressed empathy towards my clients. They were kind and gentle, understood the nature of mental illness and its symptoms, and overall had a much calmer disposition. Officers who did not receive mental health training often expressed anger, upset because they had to deal with such a call. They barked orders, were impatient and short-tempered with obviously ill individuals. This type of energy would inflame the situation as opposed to de-escalating it.

Requiring law enforcement to respond to mental health crises, is ill-advised for all involved, the officers, the mentally ill individuals and their families. Studies have indicated that people with untreated mental illness are 16 times more likely to be killed during police involvements than are those without mental illness. Officers who do not receive specialized mental health training often do not engage in de-escalation techniques and may instead incite the situation to the point where deadly force is the ultimate resolution. All law enforcement officers should receive mental health training at the academy level and additional training throughout their careers.

A new mental health crisis response system is needed to minimize the need for a law enforcement response. Such a crisis response system should include the services of trained mental health professionals who can respond to nonviolent situations. Programs such as those in Colorado, in which police officers utilize mental health professionals during 911 responses, as well as the utilization of case managers in local communities, have helped to keep offenders off the streets and out of jail. Such partnerships are desperately needed to improve the current state of affairs.

Response 190:

Dear Chairman Wyden,

Help to fund start up Fountain House Clubhouses in every Community they are the nonprofits created to improve health, increase opportunity, and end social and economic isolation of people with serious mental illness. As a Mom of a Veteran Marine with a chronic a persistent Mental illness this is my last stand and fight to have Peace of Mind. I truly can’t imagine a single Moms trying to get the care and support while working and raising children. #SOS4SMI

Response 191:

Dear Chairman Wyden,

My son's experience with mental illness, specifically schizophrenia, resulted in 14 years in prison. This blatant travesty aside, there are many other things that can be accomplished legislatively to secure effective treatment for this, for some, inevitable brain development. For one, fund programs tailored to community resources and divert people with serious mental illnesses away from criminal justice involvement. Another is make sure emergency responders are knowledgeable and experienced with SMIs. As in my son's case funds for initial treatment ran out. Therefore the Medicaid Institution for Mental Disease (IMD) and Medicare 190-day lifetime limit should be repealed.

Response 192:

Dear Chairman Wyden,

My story details the direct need to implement 3 specific TAC Policy Solutions: 1) 'Include emergency responders with knowledge and experience with SMI— including but not limited to schizophrenia, bipolar disorder, major depression, and other psychotic disorders—in both the planning and implementation of any emergency response models' 2) 'Fund programs that are tailored to community resources and divert people with SMI away from criminal justice involvement to the greatest extent possible'. 3) "Add bipartisan language to the 21st Century Cures Act to require the Department of Justice and others to collect and regularly report data involving law enforcement encounters and mental illness" The story of my bipolar daughter's death in a NC county jail in 2016 is detailed in a book I wrote and published. " The Absence of Grace' by Ada Vance can be found on Amazon. My Daughter was arrested for a bogus misdemeanor trespass and perished 7 days after incarceration by suicide. Although, it is well documented in jail records that she was bipolar, suffered with anxiety and depression and what medications she was on, she was not medicated properly nor receiving any interventions while awaiting her hearing. Finally, in an unsupervised cell she experienced bipolar mania and hung herself with a sheet. 'The absence of Grace' is her story and my woe. Also cited are NC jail stats and the official reports of Disability Rights NC. ranging from 2014-2020. The book also includes the twisting legal battle that followed my Daughters untimely and preventable death. I'm not trying to 'push' a book but THIS is why I wrote it. I want her death, her story to change the way lawmakers arrange laws that govern law enforcement. To date, Law enforcement has all the rights while the vulnerable are systematically sacrificed.

Response 193:

Dear Chairman Wyden,

In 2005 my 21 yr. old son passed from an opiate overdose after being “fired” by Spectrum services in Buffalo, NY for having a “dirty urine” + for THC. He died a week or two later.
Soon thereafter his younger brother (who was 16 months younger) who was diagnosed when young with ADHD and had high social anxiety, and was gay was introduced to Crystal meth by predatory older gay men for the purpose of party n play. There is no way to give a brief synopsis of the last 16 years except to say that no matter how many times we tried (sometimes as much as 20-30 x a month going to ER of Various Hospitals) to get him help via the Mental health system over the years we were turned away time and time again because my son did not say the right words. He was not suicidal or homicidal and I could not get him help in the Buffalo, NY area nor the State of Ohio. HOWEVER, it was VERY easy for them to arrest my son while in the state of psychosis secondary to crystal meth use. During these arrests and incarcerations, he was treated worse than an animal would be. Beaten, Abused, locked in solitary for multiple reasons, no therapeutic interventions, the showers were always broken so he could not shower regularly, nor have his hair cut or beard. My once very hygienically clean son now looked like a man from Alaska. Now here we are 16 years later. A brain hijacked by Crystal meth, a state of daily psychosis. Sexually inappropriate. Potential for great violence secondary to hurt and anger directly caused by the very system meant to help him. Although he has been linked up with all sorts of services, yet a Case manager can only manage maybe 10 minutes visiting him every two weeks! Stop throwing money at ineffective systems that waste taxpayers’ dollars and start putting it towards adequate mental health care, staff education, open up more beds and rebuild State Mental Hospitals for those with Serious mental illness and re visit the criteria for admissions into psychiatric units.
WE ARE KILLING PEOPLE with serious mental illness and substance abuse in the United States due to antiquated laws that ultimately work against a person. The ACLU has literally given people with SMI or serious mental illness the smoking gun to kill themselves. When not medicated and psychiatrically stabilized our loved ones cannot make informed decisions. They need our advocacy and help.
Each State has different Mental health laws. We need continuity of care across the whole United States and that takes Federal intervention.
Thank you for reading.
A Mother who has watched her son die over the years by the various system that was meant to protect and help him.

Response 194:

Dear Chairman Wyden,

There really isn’t enough time or space to include all the difficulties involved in getting my 27 year old son help when he needs it. And once he’s in, the hospital constantly tries to discharge him before he is stabilized. When they discharge him they have no transitional treatment plan for him. So, it’s a revolving door. It’s like getting a diabetic’s blood sugar stable then discharging them with no medical treatment plan. Insurance companies work against keeping the patient in long enough to find out which medication works the best and making sure they are stabilized. It truly is costing all of us more to do things this way. The NIMH doesn't seem to care about treating serious mental illness anymore. They've dropped the ball on it. Go to almost any city where there are homeless people and you will see the consequences of all this. Most families cannot bear the burden of the responsibility of a person with a serious mental Illness living in the home. After living with this for the past 6 years, I can see why families have to turn them out. Sometimes when I see a young homeless man walking down the street talking to himself I think to myself that was somebody's baby once upon a time. Now, we treat abandoned animals better than we treat our humans.

Response 195:

Dear Chairman Wyden,

Our son has suffered from undiagnosed mental illness since high school in 2003. Like many others self medicating to help alleviate the symptoms. After multiple doctors and treatment facilities he has made some progress however during psychotic episodes or when meds are not helping as hoped we need periodic immediate care. Due to a shortage of mental health short term compassionate options many time the only option is calling 911 and having the police respond. This option creates more unneeded trauma which leads to involuntary confinement when many times all is needed is a decent nights rest and med stabilization. Having alternatives without having to resort immediately to police becoming involved could solve several immediate short term manic episodes for those suffering mental illness.

Response 196:

Dear Chairman Wyden,

My son went to prison, Life Without Parole, committing a crime in a psychotic state. He has a diagnosis of schizophrenia. The people around him, including myself, did not have adequate education to see that he was exhibiting negative symptoms and needed treatment before he became psychotic. Please fund programs educating teachers and mental health professionals.

Response 197:

Dear Chairman Wyden,

How would you feel if your child was severely sick and a Dr. would not even speak to you, or would not even let you know how he was even doing while being LOCKED UP in a hospital or even in jail! Not even an ounce of information from a nurse or social worker. And then to discharge your loved one to the street and not even let you know. It is incomprehensible and disgusting that these United States can't do better… we are not a third world country yet we treat our mentally ill and their families barbarically. For just one moment put yourselves in our shoes!…. You can't because it's unimaginable what we go through as we watch our sick children go through the mental health system in this country. We HAVE to do better!!!! Why won't you do better?? You would and have not treated any other disease they way you treat patients and their families with a brain illness. It's time to stop dismissing the most vulnerable and their families and put an end to the heartbreak and pain that every family with a son or daughter, brother or sister, mother or father with a brain disease lives through. Thank you.

Response 198:

Dear Chairman Wyden,

"Please fund programs that are tailored to community resources and divert people with SMI away from the criminal justice involvement to the greatest extent possible." Yes, our adult daughter's story could have changed dramatically with these resources. Her child was taken from her due to her mental illness and our daughter was then thrown into jail when she tried to go see her daughter after a CPS social worker told her her daughter was very sick with the flu. What mother would not try to go see their child who is very sick? The jail experience could have been eliminated if there had been another type of program to help her with her grief at losing her child and her reluctance to take medication. The criminal justice system is no way to treat mental illness. It is horrifying that this is how we treat so many of the mentally ill in our country.

Response 199:

Dear Chairman Wyden,

My sister has been diagnosed with schizoaffective disorder. Right now, she is on a treatment path that allows her live a wonderful life. She is the bravest and best person I know. However, before she was diagnosed, her life was unbearable difficult. Her reality was different from the one others around her perceived and her symptoms and delusions caused her world to shrink into a paranoid nightmare. At the same time, my family members and I were beside ourselves with our inability to help a loved one we no longer recognized. Everything changed when we had access to our county’s mental health center (Johnson County, Kansas). It was a long and difficult road, but my family was able to navigate it because of important resources, including the JoCo Mental health centers and NAMI.

My sister and my family were lucky to have access to these life-saving resources; many others are not. People with mental health issues and disorders need access to these resources to lead better lives and be productive and members of society. As a result, I suggest the following actions to remove barriers for people with serious mental illness:

Repeal the Medicaid Institution for Mental Disease (IMD) exclusion Repeal the Medicare-190 day lifetime limit Expand federal funding for assisted outpatient treatment (AOT) Establish a national database of psychiatric beds in the U.S.
Request a Government Accountability Office (GAO) report on the extent of psychiatric boarding in emergency departments in the U.S.
Require the National Institutes of Mental Health (NIMH) to establish transparent and peer-reviewed standards for estimating prevalence rates for schizophrenia in the U.S.
Mandate periodic NIMH prevalence studies of schizophrenia, bipolar disorder, and other severe mental illnesses at regular intervals, and explicitly require that prevalence rates be accurate and comport with peer-review protocols Fund programs that are tailored to community resources and

divert people with SMI away from criminal justice involvement to the greatest extent possible Include emergency responders with knowledge and experience with SMI— including but not limited to schizophrenia, bipolar disorder, major depression, and other psychotic disorders—in both the planning and implementation of any emergency response models Add bipartisan language to the 21st Century Cures Act to require the Department of Justice and others to collect and regularly report data involving law enforcement encounters and mental illness Make permanent all telehealth coverage for Medicare recipients that were expanded under Section 1135 authority during the COVID-19 public health emergency

Thank you.

Response 200:

Dear Chairman Wyden,

My son, born in 1964, has had a brain disease all of his life. A long breech birth deprived him from needed oxygen. He did not act or behave like other children his age. He has been hospitalized so many times, been put in so many different living situations, been put on so many medications. He now lives with two other persons who have brain diseases. They live alone in a house, so there is no constant supervision. Pills and food are brought to them. He does not get the care he truly needs. This is the way it is with those who have been diagnosed as "mentally ill." Somehow, the term doesn't draw the same concern as the term "heart attack," cancer. Yet is is certainly as serious, sometimes much more serious. And how awful to have a lifelong disease...where you don't get respect, the attention, the kind of help you really need. Many persons wide up spending years in jail. Would we put a person with cancer in a jail cell. Why should we spend so many dollars on sending a man to the moon...and spend so little on a terrible illness that truly takes away his or her life even though the breathing continues.

Response 201:

Dear Chairman Wyden,

Our son has bipolar schizoaffective disorder.

Please repeal the Medicare 190 day limit, this is Is not reasonable for someone with mental illness.
Please expand Money for AOT. The mentally ill do not belong in jail, or days in ER's as our son has spent days in an ER waiting for a bed. It is stressful and makes getting help for someone teetering on the edge very dicey. The GAO should report on this statistic.
Make permanent telemedicine services permanent under section 1135.
Require therapists from county mental health programs be required to ride along and meet with those folks that have been identified from 911 calls as having a mental illness. Police and fire workers are great but do not have the knowledge to deal with the mentally ill.
Just look at our streets they are loaded with mentally ill people, they need services. They often cannot make coherent decision about there own care. As a civilized society we should do better.

Response 202:

Dear Chairman Wyden,

I am 52 year old RN, and I have a son with schizophrenia. It is a fact that the more relapses/ time not medicated are related to more severe mortality for people with SMI. The biggest problem we have encountered is relapse after relapse with my son. There is a huge amount of turnover in staff that treat severe mental illness. This is directly related to funding of programs and stress on this staff. Many times I have been unable to obtain my sons schizophrenia meds on time. This leads down a path of chaos, homelessness and self-medication with illicit drugs. This in turn causes families to fracture, as well as time lost at jobs. Please please consider the millions of Americans dealing with this every day when you vote. Thank you.

Response 203:

Dear Chairman Wyden,

I had a grandson who lived with schizophrenia for 6 years, starting with his first episode at 16. It was horrifying to see him devolve into the sad and even scary person that he became over the years. We tried to work with the system to get him help, but he ended up in and out of mental hospitals, jail, and homelessness. Finally he had had enough and took his own life to end his suffering at the tender age of 22. I miss him every day. He was a sweet, loving, brilliant, and very talented child and teenager - and then the disease ruined him, in spite of all of our efforts. The system failed him and us miserably. It just doesn't work. This is just a brief synopsis of the pains we all went through with the lack of help, having him always booted out the hospitals when he wasn't ready even though he still wasn't well but Medicaid sent him away. I even paid about $32,000 to have him go to a healing farm in North Carolina to give him time to get well, but it was too late to rescue him at that point. No one really understands what severe mental illness is and what needs to be done in the early stages of the disease in order to keep the brain from deteriorating. It's the saddest thing, and this issue needs to be addressed.

Response 204:

Dear Chairman Wyden,

Raise the pay for social workers assisting the police. This is dangerous work and they should be compensated. I turned down this job because of the low pay. Fund more psychiatric beds so people can go there instead of jails. Give people with private insurance the same access to programs that people on public assistance have. Expand Medicaid in all states.

Response 205:

Dear Chairman Wyden,

As a psychiatrist,l I recommend the following:
Repeal the Medicaid Institution for Mental Disease (IMD) exclusion Repeal the Medicare-190 day lifetime limit Expand federal funding for assisted outpatient treatment (AOT) Establish a national database of psychiatric beds in the U.S.
Request a Government Accountability Office (GAO) report on the extent of psychiatric boarding in emergency departments in the U.S.
Require the National Institutes of Mental Health (NIMH) to establish transparent and peer-reviewed standards for estimating prevalence rates for schizophrenia in the U.S.
Mandate periodic NIMH prevalence studies of schizophrenia, bipolar disorder, and other severe mental illnesses at regular intervals, and explicitly require that prevalence rates be accurate and comport with peer-review protocols Fund programs that are tailored to community resources and divert people with SMI away from criminal justice involvement to the greatest extent possible Include emergency responders with knowledge and experience with SMI— including but not limited to schizophrenia, bipolar disorder, major depression, and other psychotic disorders—in both the planning and implementation of any emergency response models Add bipartisan language to the 21st Century Cures Act to require the Department of Justice and others to collect and regularly report data involving law enforcement encounters and mental illness Make permanent all telehealth coverage for Medicare recipients that were expanded under Section 1135 authority during the COVID-19 public health emergency.

Response 206:

Dear Chairman Wyden,

There are so many barriers to treatment I've encountered as my adult sons caregiver. He has a SMI diagnosis and I cannot find psychiatrists or other providers who take Medicare. Wait lists are either closed or 5-6 months out for an appointment.
It's almost impossible to find a bed when he needs hospitalization.
My son is 47 years and I'm in my late 60's and I'm scared when I pass away my son will be in the street as there are a severe lack of group homes for individuals with mental illness.

Response 207:

Dear Chairman Wyden,

Three things that I and my family have personally experienced in terms of barriers to necessary care for our loved one with serious mental illness (diagnosis of schizoaffective disorder and bipolar disorder) are: 1. Not enough beds in facilities like hospitals where we have gone with our loved one, for help. This resulted in our loved one being discharged with active dangerous symptoms, and ultimately hurting others and eventually hurting himself. 2. The fact that Assisted Outpatient Treatment (AOT) in my County is rarely used, despite my loved one desperately needing AOT, being eligible for AOT, he has never been given AOT. Rather than AOT we are repeatedly told that our loved one will get more treatment "in prison" than in the community. Our loved one has been in prison as a result and the experiences have been horrifying. I truly believe that more funding for mental health, including beds, emergency room accountability, and discharge programs and plans. A more cohesive and smooth plan to go back into the community and be in the community once the person with serious illness leaves any facility. 3. Strive to make Jails and Prisons NOT the way we treat our seriously ill persons with mental illness. This means that police or emergency responders must have mobile crisis teams that respond to emergencies within the communities.

Response 208:

Dear Chairman Wyden,

Mick was a good friend of my son's. In his teens he developed schizophrenia. He has been jailed more than 64 times for marijuana possession. He uses this as it is one of the only things that eases his constant anxiety, paranoia and calms the voices in his head. His bizarre behaviors and extreme paranoia make it impossible for him to remain with family. His mother has been evicted due to his hand now must see him homeless while she supports his 3 year old daughter. Mick needs hospitalization or a structured setting to maintain regular medication which is near impossible while living on the streets. VA State Senator Craig Deeds paid a terrible price when his son was denied hospitalization while in crisis. His son stabbed his father multiple times and then shot himself. This story is repeated all over the country every day. Three major studies have found that 61% of mass shootings were perpetrated by mentally ill individuals. (LA Times 2018, New York Times 2000, Mother Jones 2012) Shelters and drug rehab programs will not take people with the diagnosis of schizophrenia because these individuals are unpredictable and unstable. Hospital beds are desperately needed for these individuals who are sick through no fault of their own. If created, mental health courts and group home programs such as the Gateway Program in Richmond VA can prevent crisis and provide a discharge plan for seriously mentally ill when they are released from hospital care.

Response 209:

Dear Chairman Wyden,

My son was diagnosed as having a serious mental illness which appeared after he was 18. He is 30 now and has been turned down three times for SS disability benefits. His reputation was ruined when the local police taised him, arrested him while in a state of psychosis. They then proceeded to put his name and information online. The media picked up the story which is what people see when they google his name. It cost us over $10,000 to keep him from being put in prison for his illness. Every time I ever tried to get help for him, I was told there are no beds and no place for him to live and we should just make him homeless. This has caused a huge financial and emotional strain on our family that could have been avoided. My son would have a better chance of independence if he was given options for work and financial support. If anyone feels his disease is not a disability, I invite you to live with us for a week and see what we face each day.

Response 210:

Dear Chairman Wyden,

Thank you for soliciting input for the treatment of people with mental illnesses in the US. I am a serious brain illness advocate and the mother of a 30-year-old son who lives with a severe schizoaffective disorder here in Iowa. We have met numerous barriers to care over the past 13 years that he has been sick, and he has been hospitalized twenty-six times, so far. He has tried to live "in the community" and in our home with community "services", but currently is getting care at one of our 2 state hospitals, where he has been long enough to begin to improve, for his brain to start healing, and for him to begin to engage in treatment – for the first time. We have extensive experience with the broken, siloed and inadequate system.

I agree with the recommendations from the Treatment Advocacy Center, but would add some more specific policy change and funding suggestions:

1) Codify doctors decide how long a patient needs to be in both acute care hospitals and other step-down levels of care, NOT the insurance companies. Patients not being able to stay long enough for the meds to come to therapeutic blood serum levels to allow their brains to heal causes them to not be aware of their own illnesses and to stop their meds once released. This perpetuates the cycle of repeated hospitalizations, homelessness, incarceration, victimization and often, death. It does not save money, and results in terrible outcomes.
2) End the policy of stopping SSI/SSDI benefits if someone is hospitalized beyond 30 days. They still have rent or a mortgage to pay if they are sick and in the hospital. Stopping their income is one way we actually facilitate homelessness rather than prevent it.
3) Allow HUD to subsidize housing all along the continuum of care: residential treatment facilities, group homes, stabilization beds could all be more affordable and available with subsidizing. Housing alone, without treatment, does not help people living with mental illnesses (and/or substance use disorders). We need housing paired with treatment, and this action would help provide this.
4) Fund provider education about HIPAA regulations. Most providers are so afraid of revealing PHI, they do not realize they are obligated to communicate with families of people living with serious brain illnesses in the same way they already do for other patients with brain illnesses like our elderly living with Alzheimer's Disease and Dementia. We recognize families are right to be concerned about their parents becoming unsafe an unable to care for themselves, and this same recognition needs to happen for families with adult loved ones living with these different brain illnesses that can also make them unsafe and unable to care for themselves.
5) Fund AOT (Assisted Outpatient Treatment) Programs and both Civil and Criminal Mental Health Courts to divert people to treatment, not jail. Fund jail diversion programs.
6) End the IMD Exclusion. The cost of NOT treating Schizophrenia is much higher than the cost of ending this nearly 6-decade policy that is a legal form of discrimination against people who happened to become sick with a brain illness, rather than cancer. See this study from 2020 of the costs of not treating Schizophrenia: https://sczaction.org/wp-content/uploads/2021/07/Final-White-Paper.pdf

7) End the Medicare and Medicaid Lifetime Caps for inpatient treatment. Again, this is a form of discrimination exclusive to people living with brain illnesses which are not their fault. It is morally reprehensible and has caused too many people to suffer more than they have to, and to

cost our country more than if we treated them in the first place. These illnesses are chronic and episodic, but with treatment, can be managed much more cost-effectively than if we do not treat them.
8) Raise reimbursement rates for Mental Health Professionals AND Direct Care Staff. This is difficult work, and we have too little workforce. Improving the reimbursement and wages for these providers, as well as making the agencies providing the services more financially viable is one of the ways to grow those serving the people who need treatment.
9) Fund Psychiatric Assisted Living Campuses that have multiple levels of care: acute care beds with First Episode Psychosis Programs, sub-acute care units, independent living units, group homes. We could have these on the existing State Hospital grounds. These are possible, we have created these for people living with Alzheimer's, Dementia and Parkinson's Disease. Certainly, we could create and fund these for people living with a different type of brain illness.
10) Fund Loan Forgiveness for MH Professionals of all sorts, including PA's and NP's who chose to specialize in caring for Psychiatric patients as part or all of their practices.
11) Fund expansion of Medical & MH Professional Programs of Multiple Disciplines
12) Fund more CCBHC's (Certified Community Behavioral Health Centers). Some are getting grants, but more could use them to close treatment gaps and grow their workforce and services.

Thanks for considering my input. I am happy to be reached for any further questions you may have.

Response 211:

Dear Chairman Wyden,

I support the Treatment Advocacy Center's recommendation to repeal the Medicare 190 day lifetime limit for inpatient care. My son was confined to a psychiatric hospital for more than three years. Now he faces a bill of over $1,ooo,ooo (one million dollars). He has no income other than Medicare Disability and SSI, and now risks the loss of what little savings he has. Thank you for your consideration.

Response 212:

Dear Chairman Wyden,

My son suffers from both mental illness and substance abuse and can't get good help mainly because he used up his 190 days before the age of 32. He is a high utilizer and cost taxpayers lots of money. This will just repeat itself since he can't receive the help he needs. Please STOP the 190 day lifetime limit.

Response 213:

Dear Chairman Wyden,

My son Luis Eduardo Cutie from Las Vegas, Nevada is now in Utah,nursing home because I can't find placement in Las Vegas.He is autistic and severe mental ill, severe schizophrenia. He needs long-term treatment because doesn't respond to medication. Often he becomes violent and aggressive.,unsafe keeps him at home.
He needs treatment through medicaid. Please, Luis and other people needs help!
A very worried mother,

Response 214:

Dear Chairman Wyden,

My relative, who is 29, is currently in jail for something he did while he was experiencing symptoms of schizo-affective disorder. He was arrested and taken directly to jail on August 30.

My relative is going to spend many months in jail (at least) because there is no treatment center that will take him. Treatment centers can pick and choose who they will accept because beds are I. Such short supply. The IMD exclusion contributes significantly to this shortage.

My relative needs treatment at a locked facility because of how ill he is. We need more hospital or acute care facilities that are locked to treat people who have decompensated after going off their medication or being in jail, which makes any mental illness much worse.

We need to divert people with SMI away from the criminal justice system and for some people, an acute, locked facility is needed to stabilize them.

We also need to expand funding for AOT so that people can be treated in the community. Some people need to be required to take medication while in AOT.

Thank you for your service. Please pass legislation to remove barriers to treatment for those with Serious Mental Illness.

Sincerely,

Lindsay Schachinger

Response 215:

Dear Chairman Wyden,

My story is one of persistence in spite of barriers to access and correct treatment for chronic health issues involving decades under Medi-Cal & Medicare.

Can you imagine what it is like to live 30 days to 30 days? That is what people who are prescribed anti-depressants & related are doing. You learn to expect 2-4 times a year that there will be a gap. The Dr doesn't phone in the renewal, the pharmacy doesn't have the meds, there's a holdup because whatever Medicare plan you have suddenly rejects your prescription. Meanwhile, you may experience moderate or (in my case) severe withdrawal symptoms that lay you flat out in agony. Some medications I've been on like Wellbutrin cause extreme distress when a single dose is missed.

How is one to think of the future when you are on a 30 day clock? How is one supposed to cope when access to treatment appointments are months away & months apart? What are we supposed to do in the meantime? We already have issues with asking for help. The folks in the front lines see these patterns emerge of sick people struggling, then staggering, then going critical. Often its Law Enforcement that finally gets the ball rolling for the person who has been suffering long before the event. People with guns & no behavioral heath background showing up to an extremely emotional event is not the answer.

I urge you to interview the frontline people in Behavioral Health, in domestic violence support, even the people behind the counters at liquor stores. They will share stories of watching people ping pong from barely stable to incarceration and back.

Since childhood I left behind highly dysfunctional family when I was 15. I had seen plenty of what not to do with kids. Grappling with severe depression, anxiety, ADHD, PTSD from ACE.

In my early 20's I began to seek treatment in earnest. I was caught in a cycle of deep depression episodes that were months long. I worked as a temp because I would crash every few months. Mounting "failures" in work added to my negative self image. Trying to get help required lots of paperwork, legwork & timekeeping. The churn at clinics & providers plus having to start from scratch each time lead to inadequate treatment.

By age 25, my episodes were getting worse. Post postpartum, now I had a fragile new person to care for. Struggled with going back to school, starting a career & carrying on with untreated serious heart condition & Hepatitus C complicated matters. There was no cohesion to the various clinics & specialists needed. Until things reach trauma level, getting access is a time consuming & frustrating process. Trial & error scouting for an opening. If you get a chance to get seen, access to medical records that you don't have with you is a problem (well before HIPAA). ADHD affects time management as well as organization skills. Add to that unstable living situations. Add to that being a single parent.   Even in a place like San Francisco, access to timely care is sketchy at best for complex needs.
I was lucky in 2001. The director of the Ella Hill Hutch community clinic took a dive into the comorbidities & got to a thoracic surgeon a UCMED before I died from heart failure. I had asked for mental health access before the surgery and was told none was available. Two weeks after the open heart surgery, I was in the fastest & deepest depression decline of my life (this is a known side effect of extended time under anesthesia & traumatic open chest surgery). I begged for help at the follow-up visit. I tried to get myself admitted at Langley Porter for 5150 across the street & was turned away. Was I supposed to damage myself or property?!

The soonest they could see me as a patient was more than a month out. I couldn't care for my son! I was hurting from the surgery & in despair.

In the meantime, my young son was being shuttled around the few friends I had left.
Concurrent with this nightmare was the HepC & increasing damage to my liver.
(I contacted Gilead in 2016 on my own to get Harvoni to "clear" it- by this time the damage is at Stage 3 cirrhosis - not from drink but the virus)

I bring this up because many symptoms overlap: depression, fatigue, anxiety, mental fog etc.

Even in San Francisco, with the many options for some, I did not get timely diagnosis and access to treatment until things became dire.

On top of the physical ailments, I also battled with untreated ADHD. While I did get access to medications for depression, the complications involving the churn at clinics and now that I live rural even less access to qualified professionals, the quality of my life has suffered.

I'm finding out that my diagnosed ADHD is not uncommon. Many women are not being properly diagnosed because of outdated modes of presentation. Particularly for non-white women.

I often wonder what my life would of been like if I had been able to get timely and accurate care before issues became acute.

I got my "official" disability award from SSDI in 1999.

It blows my mind how some of the world's top clinicians, and institutions can fail so badly. The wealth of knowledge, tools & people barely scratch the surface of the need.

I am also a parent of an adult child who had to endure seeing his sole support in pain & anguish for the first two decades of his life.

What could have I achieved if I had the level of support & access to treatment? Perhaps my time in college & work in IT would of been far more successful. I could of had a career instead of hitting a wall of burnout at a time when I was striving to better my circumstances.

We can't change the past. We can make it a little better for those who need timely & accurate diagnosis & community support for disabled people to thrive.

I urge you, as a native Californian, to fight for us and access to timely & effective mental health. Take the onus from the person in crisis to solve it to people with training to deal with it.

Response 216:

Dear Chairman Wyden,

Repeal the Medicaid Institution for Mental Disease (IMD) exclusion Repeal the Medicare-190 day lifetime limit Expand federal funding for assisted outpatient treatment (AOT) Establish a national database of psychiatric beds in the U.S.
Request a Government Accountability Office (GAO) report on the extent of psychiatric boarding in emergency departments in the U.S.
Require the National Institutes of Mental Health (NIMH) to establish transparent and peer-reviewed standards for estimating prevalence rates for schizophrenia in the U.S.
Mandate periodic NIMH prevalence studies of schizophrenia, bipolar disorder, and other severe mental illnesses at regular intervals, and explicitly require that prevalence rates be accurate and comport with peer-review protocols Fund programs that are tailored to community resources and divert people with SMI away from criminal justice involvement to the greatest extent possible Include emergency responders with knowledge and experience with SMI— including but not limited to schizophrenia, bipolar disorder, major depression, and other psychotic disorders—in both the planning and implementation of any emergency response models Add bipartisan language to the 21st Century Cures Act to require the Department of Justice and others to collect and regularly report data involving law enforcement encounters and mental illness Make permanent all telehealth coverage for Medicare recipients that were expanded under Section 1135 authority during the COVID-19 public health emergency.

Response 217:

Dear Chairman Wyden,

As a father of an adult child who as struggled with a mental illness diagnose for more then 20 years, I support the recommendations of the Treatment Advocacy Center in their October 27,2021 letter. Their recommendations are through and if they had been in place 20 years ago, the path that my family face would have been much better.

Response 218:

Dear Chairman Wyden,

I have a family member with untreated mental illness that has significantly affected their life. Unfortunately, this person is still not able or willing to get treatment. It has affected our family across generations. We need much more interest in severe mental illness research and more support for funding in this research.

Response 219:

Dear Chairman Wyden,

My adult family member suffers from severe schizophrenia. The system is not designed to help people like my loved ones because he’s too I’ll to know he’s ill. This is called anosognosia and is the primary reason many people don't seek treatment for severe mental illness. The changes proposed by the Treatment Advocacy Center would go far in helping families like mine. Please give serious consideration to their recommendations.

Response 220:

Dear Chairman Wyden,

I have a daughter who I haven't heard from since December 20,2021 I tried calling different hospitals and Western State Hospital.No one will answer my questions I left my info numerous times. Theodora Reyes (206)531-5874 email Theodora1458@gmail.com nobody has send me anything or called back. I know Kalema Renée Harper DOB 08/20/1986 from Tacoma, Washington is being held in one of these State run places. She was in and out of Western State at Lakewood, WA Please help me find my only daughter.

Response 221:

Dear Chairman Wyden,

Good Afternoon Committee Members.
I have lived with mental illness since childhood. Back then we did not have adequate services that could be met. Now after a long journey, we have the servioe needed, I get counseling, see my caseworker and live on my own. I will not trade it for anything in the world.
It is my deepest plea, for you to keep assisting TAC. They are making tremendous strides for all those who are challenged with mental illness. I applaud them and so should you.

Response 222:

Dear Chairman Wyden,

Dear Members,
As a parent of an adult son with Paranoid Schizophrenia, I know first hand how badly the mental health system in this country treats those with mental illness. We live in California and find it difficult to find providers who take insurance in our area. We were fortunate for the first 8 years after diagnosis, to be under the care of a psychiatrist who actually spent time talking with my son, sometimes for an hour at a time and only charged us the co-pay. Since he retired at the end of 2019, my son has gone through 5 psychiatrists trying to find one that is available to help him. If we find one that seems to work with him, they tell us "you need to find another doctor who can spend more time with you". But there are not any who will. More and more doctors do no accept insurance at all so the ones that do have very limited time to spend assessing our son. My son also has been threatening suicide and we do not have access to a provider through an answering system when it is after/before office hours. As I hope you know, mental illness does not punch a clock. Every day, every hour can be challenging and dire at times. The options for inpatient care are also sorely lacking. When one of the first things the office asks upon admission is "How will you be paying" instead of doing the assessment first, that is a problem. The care he has received in these facilities is never enough or even helpful, and the insurance

company limits the days he can spend there anyway. It is a helpless feeling to have my son be in crisis and have nowhere to turn for real help.
Do you see the problem here? Please allocate funds to serious mental illness to address this issue and treat our sons/daughters/family members/friends like they matter in this country

Response 223:

As a community-based mental health worker (for a Medicaid funded service):

(Aside from the moving to a single-payer system with no cost-sharing, which is priority number one for healthcare mental and otherwise).

An important need is reducing burnout; the main way to address this is by increasing wages--in my case this is somewhat tied to medicaid reimbursement rates, which need to be raised if this is funding most enhanced mental health service. Raise the rates and specifically tie the raises to wages/salaries.

Also: Regulating 24-hour on call requirements for particular services (including mine)--this adds greatly to burnout; even with slight supplemental pay (which is not the norm), it drives people from the profession.

Response 224:

I am interested in the work of the US Senate Committee on Finance regarding improving access to mental health and substance abuse care.

I am a New Jersey Licensed Psychologist and in 2017 I published an article that bears on this subject. The access through insurance plans is just plain inadequate. The table below tells the story.

Currently, it is almost impossible to find a practitioner who has an open slot to see a new patient in New Jersey. I am currently fielding calls from prospective patients from as far away as Pennsylvania and over one hour away in New Jersey.

Access to mental health and substance abuse care is guaranteed by two federal laws, The Mental Health Parity and Addiction Equity Act and the Affordable Care Act. The insurers, by maintaining too few in-network practitioners, are tacitly violating these federal laws. Taking the issue to the insurers would go a long way to fixing the policy of keeping the access to care adequate.

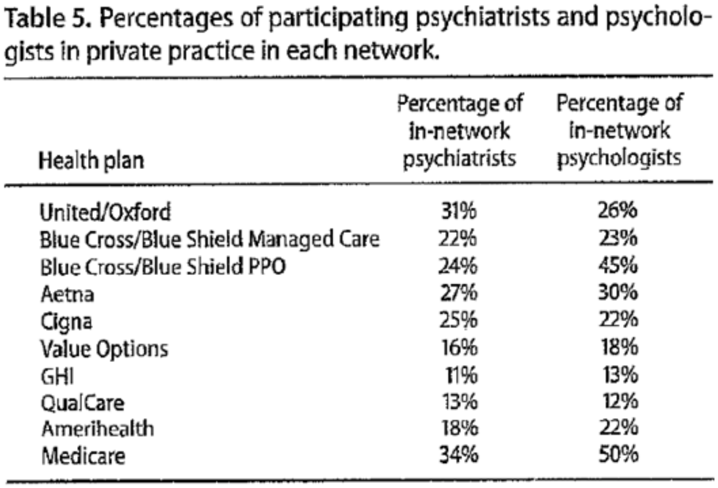

Table 5. Percentages of participating psychiatrists and psychologists in private practice in each network.

Health plan	Percentage of in-network psychiatrists	Percentage of in-network psychologists
United/Oxford	31%	26%
Blue Cross/Blue Shield Managed Care	22%	23%
Blue Cross/Blue Shield PPO	24%	45%
Aetna	27%	30%
Cigna	25%	22%
Value Options	16%	18%
GHI	11%	13%
QualCare	13%	12%
Amerihealth	18%	22%
Medicare	34%	50%

Holstein, R. and Paul. D. P. (2017) Access to Behavioral Health Care in New Jersey. Hospital Topics Vol95, No. 3, 51-56.

Response 225:

Dear Committee on Finance:

I hope you are safe, well and flourishing.

I support funding for psychotherapy of depth and insight. Improving access to such care prevents ER visits and psychiatric hospitalizations, which at best "stabilize" patients but don't result in enduring adaptive change.

We understand more and more that body and mind are interwoven systems, affecting one another. We can no longer silo mental aka behavioral health care. Widespread knowledge that care for anxiety, depression and problems in living is available is in the best interest of the populace, especially of the workforce. We are all stakeholders in this important issue.

Please don't hesitate to reach out with questions or concerns.

With regard and appreciation for your work,

Response 226:

Dear Senator Wyden, Senator Crapo and Members of The Mental Healthcare Finance Committee:

As many of the mental health and substance use disorder programs that were authorized or reauthorized as part of the 21st Century Cures Act are nearing the end of their authorization periods in Fiscal Year 2022, I thought it was important to provide feedback on two programs in particular that I believe Congress should continue to support: Grants for Jail Diversion Programs *(42 U.S.C. §290bb-38)* and Assisted Outpatient Treatment (*42 U.S.C. §290aa*).

As a mastered prepared nurse and the mother of a wonderful adult son who lives with bipolar disorder, I would like to address the importance of Assistant Outpatient Treatment as an option for those that live with serious brain disorders. I live in Massachusetts, 1 of 3 states that DOES NOT have an AOT law. Early treatment can make the difference between life and death; just last month a young mother’s life was taken when police were called to her home by a family member as her sister was in crisis. Waiting until a person becomes a danger to themselves or others before treating someone with SMI is inhumane, especially when they lack insight into their illness.

As many who live with bipolar and schizophrenia, my son does not think he is sick. With 7 hospitalizations, history has shown that leaving his mania untreated leads to psychosis, delusions and paranoia resulting in involuntary hospitalization. Last November my son’s mania was left untreated for 3 months. He was calling 3 different police stations, everyone recognized he was in crisis, yet there were no treatment options available. Our current laws gave my son the right to remain in the community denying him needed treatment. He was found roaming the hallway in his building with a pocket knife in hand when the police were called. Paranoid, he barricaded himself in his apartment yelling to the police to shoot him. This situation never should have escalated to the point that it did and could have ended very tragically. A few months ago he once again became manic; I knew I could not let his condition deteriorate given past history and the need for earlier intervention. Unfortunately my only option was to have my son arrested in hopes that a judge would recognize the need for treatment. He was court ordered for a 20 day competency evaluation in a state hospital with 14 days later added. Getting my son arrested to ensure treatment was a very traumatic experience for all, this was not an acceptable solution in my eyes nor should it be for anyone. AOT would have been a much more compassionate alternative allowing him to remain in the community. The early treatment he received proved to be beneficial in stabilizing him, taking less than a month when previously it would take 6 months for him to return to baseline. Research has shown that the more episodes someone with a serious brain disorder experiences and the longer the illness goes untreated, the poorer the prognosis.

The aftermath of involving the criminal court system has caused a great deal of undue stress to both my son who lives with a serious mental illness and our family. Most criminal courts do not have a true understanding of what it means to have a serious mental illness, criminalizing it only further deteriorates one’s stability. The days prior to appearing in a criminal court setting, my son was stable and doing well. The stress of entering the courtroom quickly had a negative impact on his stability and his behavior became quite irrational. Fortunately the judge presiding over his case understood the needs of someone living with serious mental illness and in fact is trying to establish a mental health court. Allowing him to sit at a table with his lawyer, speaking to him in a calm manner and being able to recognize that his arrest was the result of a mental health issue and not a criminal matter made all of the difference in the world. We need to end the criminalization of mental illness and in having mental health courts there is a degree of understanding and empathy that is greatly needed. Those with serious mental illness need comprehensive treatment not punishment for an illness that is no fault of their own.

SAMHSA has recognized “the need to focus on these preventable and treatable conditions, which left unaddressed, lead to significant individual, societal and economic consequences” AOT supports improved outcomes thus the availability of these programs should be widely available to all who would benefit. Having a serious mental illness is not a crime, we should no longer be criminalizing those who live with these debilitating illnesses. It is unconscionable to me that we can deny someone who is too ill to make sound decisions the proper medical care that every human deserves. The Boston Courts have recognized the need to decriminalize mental illness and with a grant from SAMHSA, was able to develop an AOT program which has been extremely successful. Massachusetts needs true AOT laws in our state so that these services are available to everyone who lives with serious mental illness, far before an arrest, arraignment, criminal record, and in many cases, incarceration. AOT programs are vital for those living with serious mental illness as they reduce incarceration, homelessness, involuntary inpatient hospitalizations and death in many cases.

I think we can all agree that seeking voluntary treatment is always preferable but there are some who simply are unable to do this because of the severity of their illness and the inability to make sound decisions. Denying someone treatment because they are too sick to ask for it is a human rights issue, everyone deserves proper medical care. It’s unrealistic to expect someone to voluntarily seek treatment when they don’t believe they’re ill.

Without AOT we are reducing psychiatric care for those that need it most like my son. With 8.3 million people affected with bipolar and schizophrenia chances are you may someday need it to help a loved one, AOT is the compassionate care that will make a difference. It not only saves lives, but significantly improves the lives of those that live with serious brain disorders and the families that care for them. I truly appreciate being able to tell my story and ask that you give strong consideration in making AOT a priority and decriminalizing serious mental illness in asking Congress for their continued support of grants for both Jail Diversion and Assisted Outpatient Treatment programs.