SSI/SSDI Outreach,
Access and Recovery
for people who are homeless

Psychiatric Disability Determinations: Adapting to Inconvenient Truths

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Introduction

The process of making a disability determination for persons with mental illness can seem almost impossible at times. Even when evaluators are sufficiently informed about mental illness, disability determination remains very challenging – both within the Social Security system and within the mental health treatment system. Pretending that these problems don't exist makes it even less likely that we will be able to change or adapt to them. The purpose of this training is to describe a set of "inconvenient truths" and a set of adaptations and nuggets to help overcome these very real difficulties of determining disability among persons with psychiatric disabilities and, hopefully improve the judgments you make. Some of you will use the materials in this training to do your job in the same way, but somewhat better informed. Some of you, hopefully, will use these materials to do your job in a different way. The most powerful kinds of changes we can make are the changes we make in ourselves starting now.

The Power of Social Security Disability Benefits

Social Security disability benefits are a powerful intervention in many people's lives. I spend an average of 2-3 hours typing lengthy Social Security disability evaluations for the people I treat. When other people tell me they don't have enough time to do that, I ask them, "What are you doing that's more important than helping someone get Social Security disability benefits?" On average, being approved for Social Security disability is worth at least $242,000 over the course of a person's life. [1] What else earns $242,000 for a few hours work? In most states Medicaid eligibility is connected to SSI eligibility and in all states Medicare is available to SSDI recipients after two years of payments. People approved for Social Security benefits can access housing, services, and medications that can change their lives. SSA benefits are our most powerful tool to get people off the streets. From government's point of view, there are massive cost savings in other services that occur once someone gets on SSA benefits. NAMI calculated that the justice system spends more government money on people with mental illnesses than do either Social Security or the mental health treatment system, so we are not only saving lives when people access benefits that they are entitled to, we are also saving local, state, and federal dollars.

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[1] If persons with serious mental illnesses are approved for benefits at age 30 for example, they may be expected to live another 25-30 years (Parks, J., Svendsen, D., Singer, P., Foti, ME, Morbidity and Mortality in People with Serious Mental Illness. Alexandria, VA: National Association of State Mental Health Program Directors, 2006). The current Federal Benefit Rate of $674 per month equals $8,088 per year times 30 years is a lifetime benefit of $246,000.

Not all consequences of receiving SSA disability benefits are positive. The label of "disabled" can have major negative effects on self-esteem and social acceptance. For example, before Social Security disability became available about half of discharged long-term state hospital patients ended up employed (Harding et al, 1987). Now, only about 5 percent of people on SSA benefits for mental disabilities return to work, and those who remain on SSA disability benefits are likely destined to a lifetime of poverty. Certainly the goal of Social Security disability was not to keep people from returning to work, but it often has that effect because it is so difficult to get on the benefit that people are afraid to lose it.

Changes Over the Years

In the decades since Social Security disability programs were established there have been several important changes in both mental health treatment/services and society that have complicated things:

- **Mental Health and Substance Abuse Treatment and Services**
  - Reductionistic approach: Mental Health has become increasingly biological, reductionistic, and medication reliant in our approach - with the striking exception of the recovery movement promoting person-centered, client-driven, and strengths-based approaches. Close doctor – patient relationships are increasingly rare.
  - Decrease in available services: Mental health services have been sharply reduced, forcing us to turn many people away and offer little more than medications to the rest. Hospitals and residential services have been especially hard hit.
  - Dual diagnosis: Mental health and substance abuse services have developed integrated dual diagnosis approaches for people with both conditions.
  - Newer medications: Pharmaceutical companies have developed new psychiatric medications that are used widely, despite only modest increases in efficacy, because their side effects are far less disabling than those of older medications. Nonetheless, "medication compliance" rates remain very low.
- **Welfare Programs**
  - Reduction in programs: Virtually all "welfare" programs have been significantly reduced leaving SSA benefits as the only option for many people.
  - Shifting caseloads: Many people in need of social services appear to have been shifted to mental health diagnoses, services, and identities.

- **Employment**
  - "Able to work" means something different than it once did: Jobs that require minimal skills, productivity, and responsibility are largely gone with automation, globalization, and the severe recession. As a result, the remaining jobs have higher requirements than they once did.

Bridging Cultures

Disability determinations require bridging the two disparate cultures and languages of the medical / mental health world and the legal world. The words "case," "client," "evidence," "objectivity," and "disability," for example, can mean one thing to mental health professionals and another to justice professionals. One of the first challenges in making disability determination evaluations is to translate medical / mental health documents into legal evidence.

Strangely enough, the most likely bridge can be found in the individuals and their work histories, since these are, in fact, the common denominator. Unfortunately, neither of our professions tends to listen much to the people we serve or to let them lead the conversation. Both prefer to interrupt and direct them, following our own lines of concern instead of theirs. Disability appeal hearings offer a unique opportunity to spend time actually talking to people and listening to the story of their lives.

When the medical and legal overlay is stripped away, what we want most to hear about is how people work. They'll tell us their stories, not in medical or legal terms, but in "person-centered" language.

Four Work History Patterns

> **Inconvenient truth:** Psychiatric rehabilitation programs have found that diagnoses don't predict ability to return to work. The only robust predictor is past employment success.
>
> **Adaptation recommendation:** Analyze the person's past work history in some detail.

There are several relevant work history patterns:

1. Never worked
2. Only work is in teens and early twenties
3. Successful work for awhile, then none
4. Never had to work and now needs to and can't

Never Worked

- Dig further into childhood history; look for lifelong impairment
- Evidences: special education, illiteracy, suspensions and expulsions, school dropout, foster care, accessing treatment services, special education services, or medications
- Accessing SSI and other services as a child usually requires involved parents or other advocates who are often missing.

> ***Nugget:*** *Children who couldn't succeed in third grade will likely become disabled adults unless there is a striking intervention and improvement.*

Only Work Is in Teens and Early Twenties

- Many severe mental illnesses begin at these ages, especially schizophrenia
- Onset of illness may be obscured by delayed treatment, adolescent rebellion, drug abuse, incarceration, military service, college, or supporting parents

Successful Work for Awhile, Then None

- Look for the reason that he or she could no longer work
- Was there an emergence of symptoms, why?
- Were there environmental factors – firing, arrest, divorce, lost housing, kids removed, layoffs, etc.?

> ***Nugget:*** *Sometimes an environmental factor is the initial cause of unemployment, but then the person can't adapt to the situation and becomes mentally ill, which causes them to remain unemployed.*

Never Had to Work and Now Needs to But Can't

- This includes people taken care of by parents, housewives, people working in sheltered settings (like uncle's business or Goodwill)
- Dig further into their roles before they needed employment

> ***Nuggets:***
>
> *The ability to sustain employment in a sheltered setting, whether family or social service agency, doesn't really indicate that the individual can work in a competitive setting even with "adaptations."*
>
> *Some jobs, especially in-home worker and telemarketing, are relatively easy to get but rarely actually provide enough hours or income to support someone at the level of substantial gainful activity.*

The Disability Determination Process

In reviewing the disability determination process, we must look at a number of necessary determinations:

- ✓ Determine if there is a mental illness
- ✓ Determine the diagnoses
- ✓ Determine what symptoms the illness is causing
- ✓ Determine the effects of treatment on symptoms and functioning
- ✓ Determine the impact of substance abuse
- ✓ Determine the functional impairment caused by the symptoms as it relates to:
  - Activities of daily living
  - Social relationships
  - Concentration, persistence, and pace
  - Episodes of decompensation
- ✓ Determine if the person is unable to work

All of the above should inform the final determination: Is the person unable to work?

This process is fundamentally a reductionistic approach to a complex task. It relies on the assumption that we can break down the person's illnesses into a series of symptoms and resulting functional deficits that determine disability. In many cases, this approach is effective. However, in other cases, perhaps especially those cases that are decided in an appeal hearing, a more holistic approach may be more effective.

> **Inconvenient truth:** If a reductionistic approach is taken, breaking someone's life down into a set of answers to specific questions, you can easily miss the big picture.
>
> **Adaptation recommendations:** Try to get an overall sense of the person; learn the story of the person's life

With a reductionistic approach, you can easily miss the big picture. Before examining a lot of specific reductionistic information, get a sense of the forest before you start looking for individual trees. From a psychiatric framework one would say: Ask some open-ended questions first to get a sense of the story of their life before diagnosing them. From a legal perspective one would say: Get a sense of the opening argument before you examine the evidence.

Nugget: *When extensive surveys of mental symptoms are done on a house-to-house basis, very high levels of prevalence of mental illnesses, about 40 percent, are routinely reported. Even select groups like college students report astounding numbers of symptoms.*

✓ Determine If There Is a Mental Illness

Inconvenient truth: There are no real tests for mental illnesses. Diagnosis depends upon both the evaluator and the person.

Adaptation recommendation: Assess the likely biases in both the evaluator and the person.

Nugget: *Psychological testing, neuropsychological testing, and projective testing are virtually nonexistent within adult public mental health systems because of funding, except occasional court-ordered examinations. Even if they would help you, you're not likely to get testing done.*

Evaluators have predetermined explanatory models that we put people's experiences into:

- Mental disorders
- Developmental processes
- Temperament / personality
- "Upbringing": social and family context
- Cultural variations

How we "explain" the person's experiences will influence whether we view them as deserving or undeserving of help.

Examples: Which of these people do you think are likely to be disabled?

Mr. A. is a 25-year-old black man diagnosed and treated with medications for the last several years for Bipolar Disorder. He has symptoms of both highs (irritability, grandiosity, disinhibition, high-risk behaviors, and high energy) and lows (depression, isolates, stays in bed, poor sleep, poor appetite, and anhedonia).

Mr. B. is a 25-year-old black man who hasn't yet "found himself" and accepted adult roles and responsibilities. He varies between thinking he can do anything, pursuing women, spending money he doesn't have, and making up various schemes and when he fails, getting discouraged, staying at home playing video games all night, and resisting his friends' attempts to cheer him up.

Mr. C. is a 25-year-old black man who has always been the class clown. He shows off a lot and entertains everyone around him, but if you catch him in a quiet moment, you'll see that he's really very insecure underneath the flamboyant front.

Mr. D. is a 25-year-old black man who was the youngest of four brothers in a single mother family. He always tried to keep up with his bothers and act bigger than he was, but they teased him mercilessly and he ended up running to his mother in tears for protection.

Mr. E. is a 25-year-old black man who grew up in the ghetto. He always had to brag to get by and tried to act older and tougher to get in a gang with his brothers. As each older brother has ended up in jail he's seemed more confused and withdrawn.

Needless to say, these descriptions could all be the same young man, and his disability determination might well be impacted by which of these descriptions was in his record. This is not to say there isn't any such thing as mental illness, but the line between "normal" and "mentally ill" isn't a sharp one and sometimes you need more than a questionnaire that catalogues symptoms.

Nugget: *Evaluators who work in "triage" settings are more likely to under diagnose to justify turning people away. Evaluators who work in "treatment" settings are more likely to over diagnose to make sure they get paid.*

Inconvenient truth: Many people reject a mental illness diagnosis even when they have them.

Adaptation recommendation: If the person's self-perception is very distorted, try hard to get longitudinal observations from other people in their lives, including their families.

Some of this is because of the stigma involved, and they don't want to be labeled crazy. Some of this is an inability to be self-reflective, to see what's wrong with them.

Nuggets:

A "lack of insight" isn't confined to psychotic disorders (people "too crazy to know they're crazy"). Many people with other disorders, including personality disorders, mania, substance abuse, obsessive-compulsive disorder and others, minimize their symptoms and impairment. Insight is often included in mental status examinations.

People who are repeatedly diagnosed in involuntary settings – police, ERs, jail, emergency teams, children's court, etc. -- are likely to have a diagnosis even if they deny it.

SSI applications from people who don't believe they have a mental disorder may have been initiated by someone besides the person. They may also emphasize relatively unimportant physical illnesses rather than mental disorders.

Inconvenient truth: Many people benefit substantially from having a diagnosis of mental illness, including but not limited to SSI eligibility. There is often substantial "secondary gain" from a diagnosis. There is often a diminished self-responsibility expected from people with mental illnesses.

Adaptation recommendation: Try to assess the person's most common coping skills. How do they try to "get what they need" in life? How do they treat people they want something from?

Nuggets:

Just because someone seeks out benefits without using treatment doesn't mean they don't really have a disabling illness. The majority of people with a diagnosis won't have any significant treatment for a wide variety of reasons, including lack of services, refusal, irresponsibility, mistrust, and an inability to use services as available. Look for usage of "walk-in" services.

Reports of "manipulative behaviors," "factitious disorders," and "antisocial personality" are more reliable indicators of the evaluator being angered by the person than of the absence of mental illness. The person probably thought they could outsmart the evaluator and they didn't. They're also likely to be somewhat immoral…but they could still be mentally ill and disabled.

Inconvenient truth: The presence of mental health professionals creates increased levels of diagnosis, and their absence diminishes it.

Adaptation recommendation: Try to get the person to describe their problems in common language instead of in clinical terms. Ask them what they thought was wrong with them before they met any mental health professionals. Ask them to tell the "story of their life" instead of the "history of their current illness." Try to get them to talk about the roles they have in life apart from their illnesses, if any.

There are high levels of mental suffering in our society. Mental health professionals tend to increase the labeling of this suffering as diagnosable mental illnesses. With increased public education, decreased stigma, and pharmaceutical advertising, the rates of diagnosed mental illnesses are increasing at an incredible rate. For example, diagnosed and medically treated major depression among adults has increased 10 fold, and bipolar disorder in adolescents has increased 40 fold. More than 10 percent of all adult Americans are taking antidepressants. Descriptions of diagnosis will shape people's experiences and self-descriptions into the symptom clusters in the diagnosis. On the other hand, a lack of mental health professionals may make it more likely that mental suffering and impairment will not be viewed and diagnosed as mental illnesses.

Nuggets:

Cultural backgrounds may substantially change how people describe their own mental suffering and their willingness to accept standard psychiatric explanations and diagnoses.

Accepting a mental illness diagnosis is often accompanied by so much hopelessness and helplessness that the person becomes more disabled. The fact that people repeatedly try to get SSA disability for a mental illness, instead of trying to take care of themselves, is likely to inhibit their chances of recovery.

✓ Determine the Diagnoses

Inconvenient truth: Since the public sector began triaging people into categories of severe and persistent mental illness (SPMI) and "worried well," the mental health system has used only a few diagnoses. Insurance companies have followed suit, and medication treatment has dominated, obscuring all other diagnoses. Unfortunately, the other diagnoses can be disabling, too.

Adaptation recommendation: Look for "secondary diagnosis" to find these other conditions.

Nugget: *The categories of mental impairment used by SSA are different from those used by psychiatrists. Although you can grant disability for organic mental disorders, anxiety disorders, personality disorders, somatic disorders, and autism and other pervasive developmental disorders, the majority of public mental health programs won't use those diagnoses or serve people who have them. If we want to help someone with one of those conditions, we routinely diagnose them with an affective or psychotic disorder instead.*

Inconvenient truth: "What you see is not what you get". Single episode mental status exams are likely to give a very limited and often misleading picture of the long-term impact of the illness. The course of any mental illness is extremely variable. Most people have multiple illnesses interacting, making it even more complicated. Most people have other impairments aside from their mental illnesses that further complicate the picture.

Adaptation recommendation: Below is a schema, "Malfunctioning Minds," to help sort out multiple mental illnesses in a different way than the Diagnostic and Statistical Manual (DSM) does that can be understood and used by nonprofessionals. If we look at all the bewildering array of mental illness diagnoses, we can divide them into three categories: illnesses with physical causes, illnesses with biochemical causes, and illnesses with environmental causes.

Malfunctioning Minds Schema

- ✓ Illness with physical causes
- ✓ In these conditions there is something physically wrong with the brain. If we could cut up the brain of someone with mental illness, there would be physical abnormalities. Sometimes this type of change can be seen on brain scans of various types. If the brain were a computer, we would say there is a hardware error. Common examples include: mental retardation, developmental disorders, organic mental disorders, head trauma, neurological conditions, brain tumors, dementia, strokes, diabetes, and brain damage from drugs and alcohol. The main treatment for these disorders is to teach people how to adapt. Medications can help symptom relief.
- ✓
- ✓ Illnesses with biochemical causes
- ✓ In these conditions the brain is physically intact but the nerve cells do not communicate with each other correctly. There are no physical tests to find these conditions. In this case, we would say that the computer has a software error. Common examples include: schizophrenia, schizoaffective disorder, major depression, bipolar disorder (manic-depressive illness), panic disorder, obsessive compulsive disorder, generalized anxiety disorder, anorexia / bulimia, and addictive disorders. The main treatment for these disorders is medication to affect the chemical processes and rehabilitation.
- ✓
- ✓ Illnesses with environmental causes
- ✓ In these conditions the brain is physically and chemically intact, but the person has been mistreated or mistreats him or herself. For these people, their problems often seem to "make sense" if we consider what has happened to them. Since we live in a society that mistreats so many people, these conditions are very common. Common examples include: PTSD, personality disorders, victims of child abuse and neglect, victims of domestic violence, rape victims, victims of violent crimes, adjustment disorders, and "broken hearts". The main treatment for these disorders is to help people with emotional healing and to provide "corrective emotional experiences," often including therapy. Medications are primarily provided to help them to get along with other people and not be quite so distressed and disruptive.

Nugget: *Even though much of our current mental health field calls the conditions with biochemical causes "major mental illnesses" and sometimes disparages conditions with environmental causes as the "worried well," there are people who are clearly disabled with any of these conditions.*

There are a few serious limitations of this schema:

- Some conditions, like ADHD, autism, social phobia, and intermittent explosive disorders are difficult to place clearly in any one category.
- The three categories interact with each other. For example, serious childhood sexual abuse, ostensibly an environmental cause, can lead to physical and hormonal changes. On the other hand, the chemically caused disorder of panic attack can sometimes be successfully treated with the "environmental" treatment of behavioral therapy.
- Some conditions have features that clearly seem to belong in more than one category. For example, anorexia features a distorted body image that seems biochemically caused, but it occurs almost exclusively in the environmental context of an overabundance of food.
- Many people have more than one condition, like a Chinese menu. Try to develop a history of how these illnesses progress over time, but more importantly, try to determine which diagnosis is having the greatest effect at present regardless of which one came first.
- Our present society, including mental health professionals, is heavily invested in moving conditions from environmentally caused to biochemically caused and "needing medications." "Common human misery" is now often diagnosed as Major Depression or Bipolar Disorder and treated with medications, while nothing is done about what's really wrong in peoples' lives and in our communities.

Nonetheless, this schema can help describe complicated conditions.

Malfunctioning Minds: Examples

Mr. F got hit in the head when he was 27-years-old and suffered a skull fracture and a subdural hematoma; he was in a coma for two days. Since then he can't sleep regularly, he's irritable and anxious around other people, and his memory is impaired. He was diagnosed with a post concussive organic brain syndrome. Since the injury he has become isolated, avoidant, depressed, helpless, and he even tried to kill himself. He developed a Major Depression. To cope with that, he started drinking heavily, which makes him more depressed. He does not seem to have alcoholism, but he is making himself worse by drinking. He's ended up destitute and homeless which has beaten him down even further. He takes medications to help with the depression, to sleep, and to decrease interpersonal irritability.

Miss G grew up in South Central Los Angeles in severe poverty. She was subjected to lots of child abuse, neglect, violence (including several family members being murdered), and poor schools. Despite being bright, she dropped out of school to sell and use drugs. At age 24, she began to hear voices every day, experienced mood swings, and became aggressive, including stabbing her sister. She was diagnosed with schizoaffective disorder, hospitalized several times for being aggressive with her family, and prescribed medications. She takes the medications regularly and they do help a lot.

Miss H also had an abusive, neglectful, traumatic childhood. She was bounced around between various abusive, alcoholic family members and uncaring foster and group homes. She was considered to be a behavioral problem throughout childhood, she was diagnosed with ADHD, and she was prescribed medications. Her education was very fragmented, and she did poorly in school. She can't do simple arithmetic to make change or read a menu; this earned her an additional diagnosis of learning disability. When she was 20, her six-month-old daughter was removed by Children's Services because Miss H had no money and nowhere to live. She was heartbroken. She became irritable, depressed, and suicidal with impaired appetite, concentration, and sleep. She was diagnosed with Bipolar, Type 2 Disorder and Borderline Personality Disorder. She is participating in parenting and anger management classes. She is also taking antidepressants and a small dose of antipsychotic medication to calm her.

Notice how for each of these three people, I've described a history that includes which kind of illnesses occurred, the major impairments and the role of medications and other treatments. This may be easier to work from than a standard five-axis DSM diagnosis.

Inconvenient truth: Most doctors make a diagnosis in only a few minutes and many diagnoses are incorrect. Very few settings have doctors do full assessments.

Adaptation recommendation: Almost all charts do have a psychiatrist confirming some diagnosis to demonstrate "medical necessity"; this makes the visit eligible for payment. After you find that document, move on to collect as many "nonmedical" evaluations as possible. Go beyond the initial assessments, looking for triage assessment documents, vocational rehabilitation and disabled student referrals and evaluations, children services custody evaluations, and other court evaluations.

Nuggets:

Assess the quality of a SSA paid psychiatric consultation before you accept their conclusions. These evaluations may be done very rapidly and inaccurately. The consultants have no relationship, commitment, or ethical treatment commitment to the person they are evaluating. Nor do they have a long-term view of the person. Also, these are the settings in which people are most likely to distort themselves in a way to demonstrate disability (or even to prove to others that they don't really have any disability), since they have no other reason to be seeing this consultant and no relationship with them.

Decide what kind of information you most need to complete your evaluation before you order an outside evaluation. Psychiatrists are best for making diagnoses and listing symptoms. Psychologists do psychological testing (e.g., IQ testing) better. Neurologists evaluate physical brain damage and seizures. Functional evaluations are likely to be done best by occupational therapists and rehabilitation counselors. Interpersonal problems and personality disorders are evaluated by a variety of therapists. Don't discount evaluations done by social workers (LCSWs), nurse practitioners and physician's assistants as they typically spend more time with patients and may know more about an individual's functioning in a variety of settings.

✓ Determine What Symptoms the Illness Is Causing

Inconvenient truth: Almost every mental symptom can be associated with almost any diagnosis. The list of symptoms you can find under the diagnosis in the DSM or The Listings may or may not apply to the person you're evaluating. They often have many other symptoms not on the list.

Adaptation recommendation: You can collect lists of symptoms from the chart notes and the reports. Unfortunately, the chart is likely to be written in medical language you'll have to translate into understandable terms.

Sample List of Symptoms	
Psychosis	hallucinations, delusions, paranoia, tangential / loose associations (confused thinking)
Depression	sadness, slowness, hopelessness, blunting, anhedonia (inability to experience pleasure)
Mania	grandiosity, hyperactivity, energized, pressured speech, reckless behavior
Anxiety/fear	generalized, social avoidance, panic attacks
Obsessions/compulsions	checking, washing, rituals
Mood instability	lability (changing over minutes or hours rather than over weeks)
Irritability	avoidance, aggression
Suicidal / homicidal	thoughts or actions
Impulsivity	explosive behavior, ignore consequences, risk taking
Self-destructive	masochistic, dependent, abusive relationships
Harm others	even those they care about, regrets, taking vs. avoiding responsibility, criminality
Poor decision making	intellectual deficits, limited self-evaluation, executive dysfunction (lack of control of cognitive processes)
Communicative dysfunction	speech patterns, expressive and/or receptive
Cognitive dysfunction	developmental delay, dementia, delirium
Personality disorders	conflicted, abusive relationships, isolation, family antagonism
Trauma history	flashbacks, nightmares, intrusive memories, avoidance
Somatic symptoms	sleep, appetite disorder, sexual dysfunction, conversion symptoms (emotional distress transformed into physical symptoms)

Can you translate all of these terms into understandable language?

> ***Nugget:*** *Schizoaffective disorder is a poorly defined diagnosis that is being used widely to describe people with lots of symptoms who don't fit into any other diagnosis.*

✓ Determine the Effects of Treatment on Symptoms and Functioning

"A diagnosis is not a destiny." The choices each person, service provider, social policymaker, and Social Security evaluator makes can profoundly impact a person's course of illness and disability.

Even though the vast majority of people with mental illnesses could recover substantially and many could even work, less than five percent of people with mental illnesses on SSI have historically stopped receiving benefits because they returned to work. Very few people will ever get the services that would help them recover. Some people don't believe recovery is possible, so they don't aggressively pursue recovery. Some people don't work because they're afraid of losing their SSI after it was so hard to get.

> **Inconvenient truth:** In many states, Medicaid is not available to those without SSA disability benefits. Without insurance, they cannot access treatment that would help them to recover until after they get SSI. Similarly, they don't have money to pay for board and cares or other group homes, residential substance abuse treatment programs, or sober living homes until after they get SSI to pay for them. With cuts in other welfare systems and a lack of funds for housing, people who are disabled often become homeless or involved with the justice system and live in jails. Some stay with families while others are hospitalized recurrently. Paradoxically, they may be a lot less disabled after they get SSI and Medicaid than they were while they were applying for benefits.
>
> **Adaptation recommendation:** "Protective factors" – having stable housing, having enough money to last the month and some for emergencies, family support, support and advocacy from another adult, having purpose and roles outside the mental illness – are more likely to support resilience than treatment. Assess for these "protective factors". If they have very few of them, they're more likely to remain disabled and unemployed.

Inconvenient truth: Unlike 12-step recovery programs, many mental health services have become almost entirely reliant on medications.

Adaptation recommendation: Medication records are likely to report only symptom levels and distress. About a third of people in treatment are receiving "meds only," but for the rest there may be other providers involved who are more focused on people's overall life and functioning. There are a variety of rehabilitation, recovery, peer-run, wellness center, and clubhouse programs in many places that spend far more time with people than their psychiatrists do. These programs may be the person's main hope for employment. However, they typically do not have professional standard records and may not have records at all; nonetheless, they can be very informative. These programs may provide progress reports, if requested.

Inconvenient truth: Medication notes are written as rapidly as possible. They are designed to ensure payment for the visit, not necessarily to track treatment. Handwritten notes may be very brief or illegible. Computerized notes may use a lot of repetitive "speed notes" or checklists with very little individualized material. As a result, it often can be difficult to glean coherent information from "medical records."

Adaptation recommendation: Although there are a large number of psychiatric medications and more new ones are released every year, there are only a few "classes of medications": antipsychotics, mood stabilizers, antidepressants, anti-anxiety / sleeping medications, stimulants, and "side effect" pills. Knowing what category of medications someone is prescribed may indicate the purpose of the medication and the targeted symptoms.

Targeting Symptoms	
Medication	**Purpose**
Antipsychotics	reduce psychosis and to "tranquilize"
Side effect pills	counteract side effects of antipsychotics (primarily older meds)
Mood stabilizers	reduce mood swings and mania
Antidepressants	reduce depression and anxiety
Antianxiety / sleeping pills	decrease anxiety and improve sleep (can be addictive and abused)
Stimulants	decrease hyperactivity and poor attention (more likely to be addictive and abused)

The below chart lists some of the most commonly prescribed medications.

Commonly Prescribed Psychiatric Medications	
Antipsychotics Typicals Atypicals Side Effect Prolixin Clozaril Cogentin Haldol Zyprexa Artane Stelazine Resperidone Symmetrel Navane Seroquel Benadryl Trilafon Abilify Inderal Loxitane Geodon Serentil Invega Mellaril Saphris Thorazine Latuda	Mood Stabilizers Lithium Depakote Tegretol Trileptal Lamictal Neurontin? Klonipin? Atypicals? Omega fatty acids?
Antidepressants Tricylclics SSRIs Others Elavil Prozac Trazadone Imipramine Zoloft Serzone Desipramine Luvox Remeron Tofranil Paxil Wellbutrin Sinequan Celexa Strattera Ascendin Lexopro Effexor Anafranil Pristiq Cymbalta Nardil Parnate ECT – Shock therapy	Antianxiety / Sleeping pills Benzos Others Nonaddictive Valium Xanax Buspar Ativan Halcion Benadryl Klonipin Sonata Vistaril Dalmane Lunesta Restoril Ambien Librium Tranxene Serax
Stimulants Ritalin Methylphenidate Dexedrine Cylert Concerta Provigil	

Inconvenient truth: Medications are usually prescribed to reduce symptoms and disturbing behaviors, not with the overt goal of improving function. As a result, sometimes medications increase disability instead of reducing it.

Adaptation recommendation: Try to get a sense from the person whether they "take medications" or "use medications." If they have a substantial voice in their medications, their medication goals and motivations are more relevant. Do they take medications to "feel better" or blunt feelings; to be able to sleep or even sleep away their lives; not get angry and avoid getting into trouble or stay stable – or do they take them to enable them to do more with their lives? Ask about what they're able to do while taking medications that they can't do without them.

Nuggets:

Overt "positive" symptoms like delusions and hallucinations cause more social rejection and exclusion, whereas subtler "negative" symptoms (low energy, motivation, diminished interpersonal interactions and cognitive deficits) are actually more functionally disabling. Most medications, especially antipsychotics, primarily alleviate "positive" symptoms.

People often blame their medications for causing problems that are actually symptoms of their illnesses. Investigate further to see if their complaints are more likely to be symptoms than side effects. These people are also likely to repeatedly stop their medications against their doctor's advice.

Inconvenient truth: Medical charts are likely to minimize side effect reporting.

Adaptation recommendation: The most likely relevant functional impairment due to medications is over sedation.

Nuggets:

Doctors sometimes intentionally over sedate people to slow them down (chemically restrain them). This is so that others can tolerate them. Check the record for lots of behavior complaints, police calls, emergency psychiatric team calls, evictions, or failed placements.

The combination of high doses of benzodiazepines, sleeping pills, pain relievers and/or muscle relaxers may indicate someone is trying to use meds, usually unsuccessfully, to deaden unbearable anxiety, emotions, and/or pain. This can cause additional disability, including sedation, slow reflexes, cognitive impairment, or decreased motivation. They may also complain that the doctor doesn't understand how bad they are and won't give them enough meds, or they "doctor shop." Keep in mind, however, that it's likely that there is an underlying disabling disorder or these individuals and their doctors wouldn't have gotten into this mess.

Clozaril has the most side effects and sedation of any medication and it can be lethal. It is only used as a last resort medication. If someone is on Clozaril, it is very likely they are disabled and that the Clozaril is causing side effects.

Check for the usage of "old antipsychotics," including: Thorazine, Mellaril, Serrentil, Loxitane, Trilafon, Navane, Stelazine, Haldol, and Prolixin. If someone is on these medications, it's likely that either: 1) They have been on medications regularly for a very long time and have a chronic condition, 2) They are intentionally being sedated, or 3) They are in a treatment system that reduces costs by heavily restricting the doctor's choices of medications.

Seroquel is the only one of the newer "atypical" antipsychotics that is also very sedating. As a result, it is often used in small dosages (usually 25 – 100 mg) to help people sleep or to sedate people. It is a very popular medication because it provides sedation without being addictive. The other newer antipsychotics are only likely to be over sedating in very high dosages.

✓ Determine the Impact of Substance Abuse

Inconvenient truth: Both the mental health and the substance abuse treatment systems have given up on trying to separate out mental illnesses and substance abuse conditions, dealing with them together as "co-occurring disorders" and seeing the people as "dually diagnosed." The SSA policy regarding people with substance use disorders (set by Congress) can be seen in housing policy, Medicaid policy, and other benefits. These policies reflect society's view of substance abusers as having criminal problems rather than medical problems. People with mental illnesses are viewed by our society as disabled and deserving of help, whereas people with substance abuse conditions are seen as hurting themselves intentionally and not disabled or deserving of help. The reason that people with substance abuse disorders are not eligible for SSA benefits is clearly moral and not medical. When a person has both disorders, decisions are more commonly made on moralizing grounds than on any medical grounds

Adaptation recommendation: Accept that morality is likely to influence your sense of whether the person who is abusing substances is "deserving" of disability benefits and keep it in perspective as you attempt to determine if the person can work.

Nuggets:

There are a number of personal characteristics that can affect our judgment of deservingness, including: gratefulness, cooperativeness, aggressiveness, being female, tearfulness, small size, educational level, physical attractiveness, and race. In addition, there is our own ability to empathize and sympathize with an applicant. Do a quick check of these factors to try to see how much they have influenced your impression of an applicant.

Almost no one thinks that they aren't deserving of help. They will fight your decision and similar decisions others have made about them by trying to convince you that they really are deserving of help.

Inconvenient truth: It can be extremely difficult to separate out the role of substance abuse from mental illness as the two disorders heavily impact each other.

Adaptation recommendation: The three main strategies for determining if substance abuse is material to their disability are:

- Determine if the person was disabled before they began using drugs
- Determine if the person would have permanent mental effects that would still be disabling even if they stopped using drugs now
- Determine if we think the person would still be disabled if we imagine their life without substance abuse.

Here are three approaches to each of those strategies:

The person was disabled before they began using drugs.

- Look for childhood impairment (e.g., slow development, childhood behavioral problems, school suspensions and expulsions, childhood mental health treatment, special education, learning disabilities, foster care, severe childhood trauma and abuse)
- Try to assess the age that drug abuse took over their lives
- Look for onset of disabilities (like school drop-out, inability to work, children removed), legal problems, and changed social connections
- If there's no clear period of functioning before the onset of substance abuse, than it's less likely they could ever function

Nuggets:

If a person can provide a detailed history up to a certain age, but then the story becomes vague and hard to follow, that transition likely marks the onset of either substance abuse or serious mental illness.

When someone's life is taken over by drugs, they are likely to stop growing emotionally because they rely on altering their feelings through chemicals instead of relationships and emotional effort. As a result, many people's emotional maturity is stunted. The age they "act" may provide clues about when the substance abuse became severe.

Even if the person stopped using drugs now, they have permanent mental effects that would be disabling.

- Look for physical consequences of substance abuse – e.g., seizures; liver damage, including cirrhosis; damaged heart valves from infections from injecting drugs; traumatic brain injuries; heart attacks; strokes; or kidney damage
- If the person used enough drugs or alcohol to cause serious damage to the body, there is probably damage to the brain as well
- Look for memory difficulties that persists even when the person is not drunk or high
- More than emotional changes or anxiety, memory loss is likely to indicate permanent damage

> ***Nugget:*** *Each drug has its own chronic brain damage syndrome. Alcohol has the most obvious one, including blackouts, DTs, withdrawal seizures and hallucinations, decreased alcohol tolerance, memory loss, tremor, decreased coordination and balance, and eventually psychosis.*

If we imagine the person's life without substance abuse, we think they would still be disabled.

- This is by far the hardest strategy because substance abuse is usually much more disabling than the individuals, their families, or their treating staff thinks it is
- This is not just a question of denial and minimizing; it's very hard to know who anyone really is under the impact of substance abuse
- Your best chance of trying to figure this out is to look for a period of prolonged sobriety – at least six months – to see what they're like

> ***Nugget:*** *The most likely settings to see prolonged sobriety - jail, prison, substance abuse programs and sober living programs - aren't necessarily always actually sober. Also, these periods are very different from "normal life," so it's difficult to extrapolate from those experiences. Nonetheless, if someone is repeatedly referred for mental health treatment from those settings, there's a high likelihood that they have substantial underlying mental illnesses.*

✓ Determine the Functional Impairment:

Inconvenient truth: The vast majority of mental health treatment programs do not routinely conduct functional assessments of the people they serve. When you request records, they are likely to send you their chart records and not spend the time to actually do a disability report in addition.

Adaptation recommendation: You may want to do your own assessment of functioning using the Social Security forms and by interviewing the person yourself.

Nugget: *Occasionally the system does do functional assessments. The most common are psychological testing for children, vocational rehabilitation assessments (usually in a separate system and chart from the mental health record and not shared), or occupational therapy assessments. However, people who are trying hard to get SSA benefits aren't likely to be connected to occupational therapy or vocational rehabilitation.*

– Activities of Daily Living (ADLs)

Inconvenient truth: Almost no one fills out the Activities of Daily Living forms completely and accurately enough to really assess the individual's functioning.

Adaptation recommendation: It's more revealing to ask details about how someone does a task than asking if they do it.

Here are some example potentially revealing questions:

When you do laundry, do you:

- Sort the clothes into lights and darks and delicates?
- Know how much change to bring with you?
- Know how long the entire job is going to take?
- Bring hangers and something to carry folded clothes back home in?

When you grocery shop, do you:

- Make a shopping list before you go?
- Use coupons?
- Pick out food as you go through the store or backtrack a lot looking for items one at a time?
- Have to go at strange times to avoid crowds?
- Ever leave your groceries because the check-out lines were too long?

- Have to put back groceries because you didn't have enough money for what you picked out?

When you take the bus, do you:

- Go alone?
- Only go on routes you've been before, or how do you learn new routes?
- Bring correct change?
- Use monthly passes?
- Use transfers?
- Have to avoid crowded times of day?
- Sometimes miss your stop and have to come back?
- Know the schedule or just wait for the next bus?

Notice how these types of questions help assess planning, problem solving, decision-making, social anxiety, and ability to learn new tasks in considerable detail, much more so than typical mental status examination questions do.

Nuggets:

Many men have virtually no training in these sorts of ADL skills, nor any daily responsibilities for doing them. In those cases, inabilities may not be very revealing.

Raising children has similar demands to working and usually people, especially mothers, are very motivated to raise their children. Assessing their ability to raise children may give important insights into their ability to work. Turning children over to other family members or having them taken away is a bad sign. On the other hand, someone who is a successful single parent is likely to be able to work.

People who have been homeless a long time often have entirely different activities of daily living than the rest of us do. Ask questions relevant to their lives – going to churches, food banks, shelters, welfare offices, or clinics; building outdoor shelters; caring for animals; keeping warm; getting showers; finding clothes; getting donations, and other "survival" activities.

– Social Relationships

Inconvenient truth: Assessing social relationships is very difficult, especially using clinical records that assess people in a prescribed client role with trained professionals. Many people act differently in a mental health clinic than they do at work or other places.

Adaptation: Try to assess people's social relationships in a variety of roles and settings.

You can break down your assessment into three areas:

- Disruptive behavior – for example:
  - talking to oneself, confused speech, pressured speech, talking about delusions and hallucinations, or mania
  - emotional outbursts, aggressive outbursts, violence, obscene behavior
  - panic attacks, compulsions,
  - extremely poor hygiene
- Social deficits – for example:
  - lack of emotional connectedness or response to social cues
  - severe shyness, withdrawal
  - blunted emotions, limited speech, no smile or laughter
- Fear and avoidance – for example:
  - too scared to talk to people, won't ask for help or instructions, freezes around other people
  - can't go to job interviews, doesn't go to unfamiliar places, isolation
  - low self-esteem, paranoia

The person has to be able to function *in work settings and roles* in all three areas to be able to work.

Nuggets:

Many people are less fearful and avoidant with family and in mental health settings, but also more disruptive.

Assessing how people interact in a disability hearing with you may not be very revealing of how they might interact with others in a work setting.

– Concentration, Persistence, and Pace

Inconvenient truth: Assessing these factors in clinical settings is very difficult and easily manipulated by people experienced with mental status exams.

Adaptation recommendation: Assess their ability to complete tasks that they have a vested interest in completing and that aren't connected to a "disability exam."

Nuggets:

The most common "tests"(serial 7's – subtracting 7 from 100 and going down from there; remembering three common objects; naming the presidents; taking a paper in one hand, folding it and returning it in the other hand; etc.) were originally intended to be warning indicators to investigate further, not complete exams in themselves. Many people have seen these tests over and over again. This is an easy opportunity to "act crazy."

In most clinical situations the clinician takes responsibility for maintaining concentration, persistence, and pace of the session and rarely stays silent or allows the person (without supervision or direction) to focus themselves. A work supervisor won't do that. If clinical staff notice the person not keeping up with them, they may describe them as distractible, having tangential thinking, needing to have questions or instructions repeated, responding to internal stimuli, or dissociating.

Notes commonly describe compliance with "informed consent" processes far beyond the person's actual capabilities.

Questions that reflect tasks that have value to the person should be more revealing of their true functional abilities. For example:

- Do they remember their appointments?
- How do they fill their prescriptions?
- Can they wait at the pharmacy?
- Were they able to fill out the SSI paper work?
- Can they buy a bus pass?
- Can they reach an actual person on the SSA phone system?
- Can they handle clearing a warrant in court on their own?

Notice that when concentration, persistence, and pace are assessed "naturalistically" there is overlap with the Activities of Daily Living section.

Nuggets:

Many people can concentrate, persist, and maintain pace much better with someone else working alongside them. They may be able to complete tasks with a clinician or family member that they can't do alone. They may be able to work for a family member or in a sheltered group placement, but not in a normal work environment.

Try to determine what frustrates other people about them, including family and clinicians. Often the answer reflects some inability to concentrate, persist or maintain pace.

The ability to concentrate, persist and maintain pace is sometimes dependent on how nervous or stressed the person feels. They may be able to do something on their own, but not with the pressure of a boss. Try to assess the difference stress makes on the person's level of functioning.

Inconvenient truth: "Persistence" at work isn't required just for minutes or even hours. Many people start a job enthusiastically and energetically only to find themselves losing concentration, persistence, and pace a few weeks or even months later and losing the job as a result.

Adaptation recommendation: Investigate histories that have multiple short-lived jobs. What may on the surface look like a lot of work experience, may actually be a lot of work failures due to poor persistence.

Nugget: *Many people with mental illnesses have histories of numerous short-lived jobs. Sometimes this is a sign of repeated interfering "decompensations," but often it's a sign of inability to persist at work. Many rehabilitation programs focus on "work hardening" to build persistence so their clients don't keep losing jobs that are hard to get.*

Inconvenient truth: The concept of "pace" of work was designed primarily for people with developmental disabilities who could work in sheltered settings, but not at a pace that made them productive enough to be competitively employed even at minimum wage. A combination of inadequate education, social factors, automation, globalization, and downsizing has left a substantial proportion of our society unable to be productive enough to be competitively employed including many people with mental illnesses.

Adaptation recommendation: Try to assess their likely work productivity as much as their speed of task completion. Can you see this person as an employee who "pulls their own weight"?

Nugget: *Departments of Vocational Rehabilitation and Disabled Student's Offices at community colleges don't like wasting their time and money on people who have virtually no chance to succeed, even though they are mandated to serve seriously disabled people. If they refuse to serve someone or discharge them after repeated failures, it likely indicates an assessment that the person cannot be rehabilitated or become self-supporting.*

- **Episodes of decompensation**

Inconvenient truth: The entire concept of decompensation is based upon the idea that the illness can be stabilized or put into remission, and then something happens that triggers a decompensation making it worse again. This idea is more relevant to acute illnesses, rather than to chronic illnesses. After the onset of a serious mental illness, many people are never really symptom free, even with good treatment.

Adaptation recommendation: Try to assess the range of functioning – including both "good days" and "bad days". To be able to hold a job, even one with "sick days," employees must be able to work on their "bad days" too. People cannot expect to hold a job working only on the days they feel well, they have to work whenever the boss wants them to work.

Nugget: *Many people, families, and professionals believe that "stress," especially the stress of returning to work, will trigger decompensations and therefore should be avoided. There is very limited evidence that this is true; the "stress" from being bored, isolated, overprotected, unemployed, and poor is often worse than the stressors the person is avoiding. Nonetheless, that belief leads to widespread avoidance of work and resentment of being told to return to work because of fears that "it will make me sick again if I try."*

Inconvenient truth: For the most part, hospitals and emergency rooms must respond to people who are disruptive, rejected, suicidal, or those who have nowhere else to turn, rather than to someone who is simply decompensating. This means that some people may have serious decompensations but they're not hospitalized because they aren't dangerous or difficult, while other people are repeatedly hospitalized for being dangerous or difficult who aren't actually experiencing a decompensation of a mental illness.

Adaptation recommendation: Hospitalizations and emergency contacts are more likely to reveal problems with activities of daily living or disruptive social relationships than decompensations, but that can be useful information too.

✓ Determine If the Person Is Unable to Work

Inconvenient truth: There are many reasons that people are unable to work besides medical or psychiatric disability. However, medical or psychiatric disability is one of the few reasons that make someone eligible for a lifetime monthly check that's almost enough to live on. There are some people with mental illnesses for whom their inability to work is directly caused by their illness and there are other people with mental illnesses who are unemployable for less direct reasons.

Adaptation recommendation: Try to determine the reasons why the person with a mental illness isn't working. Remember, your final decision can be affected by whether you believe the person "deserves" disability benefits.

Nuggets:

It's often claimed that the reason many people aren't working is because they're lazy; and there is an assumption that without a check they're more likely to get a job because they'll need one. This is probably true for some people. However, by the time applicants get to a hearing, they've been unemployed for at least a year and often much longer. Even so, they still haven't gotten jobs. At this point, it's unlikely that another denial will result in people going to work.

You can sometimes sense when service providers believe that a person deserves disability benefits when you see how much effort they've put into assisting with their case. However, with staffing shortages, many staff are too overwhelmed to help even people they do think are eligible.

Inconvenient truth: It is a long and difficult road back from long-term unemployment for people with mental illnesses. Not only do they have to overcome their symptoms, but they also have to rebuild their lives. This can often be more challenging than just treating their illnesses. Other services that would support their recovery are often unavailable.

Adaptation recommendation: Project into the future. Try to imagine what they would have to rebuild in order to become a worker again. Has too much damage been done?

Examples from My Practice

Here are a few recent examples from my practice of people who have applied for Social Security benefits.

Mr. F had a good upbringing and went to college to be a musician. He dropped out of school after a couple years to seek the lights of New York. He worked for about eight years playing piano and singing, supplementing his income with retail work. He traveled around the world, performing on cruise ships and at hotels. At one point he was attacked, suffering a skull fracture and subdural hematoma. He was in a coma for two days. Since then he can't sleep regularly, he's irritable and anxious around other people, and his memory isn't good enough to play piano very well or learn new songs. The attack was 20 years ago and he hasn't gotten any music work since, yet he still thinks of himself as a musician. He's isolative, irritable, and loses retail jobs within a few months. He has been homeless for eight years. In this time, he has been drinking too much, seriously depressed, and bitter about how his life has turned out. He has never married or been in a serious relationship, had children or friends. He has given up.

Miss G grew up in South Central Los Angeles in poverty. She never knew her father and her mother was on welfare. Her brother and her boyfriend were both shot and killed in drive-by shootings. She dropped out of school in 11th grade for the "fast life" of selling drugs. She was pregnant by 18, but her mother mostly raised the child. She lives with her mother along with her unemployed sister and two of her kids. At age 24, she began hearing voices every day and was diagnosed with schizoaffective disorder. She was hospitalized several times for being aggressive with her family. Once she started taking medications regularly, she found them to help a lot. Nonetheless, she tried to stab her sister. She was sentenced to one year in prison where she received mental health treatment and was quiet throughout. She was recently released from prison and wants to rebuild her life starting with a GED at age 35. (Or, how about if she's 58?)

Miss H bounced around throughout her childhood between various abusive, alcoholic family members and uncaring foster and group homes. She was determined to be a behavioral problem and diagnosed with ADHD and given medications. She did poorly in school, which was very fragmented. She cannot do simple arithmetic, make change or read a menu. She aged out of foster care at 18 and "couch surfed," usually trading sex for a place to stay. When she got pregnant, she stayed at a program for pregnant women, but after her daughter was born, there wasn't any subsidized housing available. Since she had nowhere to live, Children's Services removed her daughter. She was heartbroken because she'd promised herself that she would never let what happened to her, happen to her child. She became depressed and suicidal. She is now trying to rebuild her life so that she can get her daughter back. She is participating in parenting classes and an anger management group. She is taking antidepressants and a small dose of antipsychotic medication to calm her, but has no income and no job prospects.

These are the same three people that I described earlier in the "Malfunctioning Minds" (Determine What the Diagnosis Is) Section. If you look back, you will notice how those "illness centered" descriptions, even though they are relatively "user friendly," are quite different from these "person centered" descriptions. Sometimes a "story of a life" is more informative than a "history of present illness." Sometimes looking at people from a recovery perspective provides a clearer picture than viewing them from a medical perspective.

We are all trying to do an almost impossible task – in your case, making disability determinations, and in mine, helping people to recover. We can all use as clear a picture as we can get.