# Young Adults and the Mental Health System

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Nowhere are our mental health system's weaknesses as glaring - or as important - as in the way we care for young adults with mental illnesses. Early problems with diagnosis, treatment, and relationships with caregivers can easily become perpetuated and magnified over time so it's very important to get these things done properly, right at the beginning. But, for a variety of reasons, our system has a very difficult time getting off on the right foot with mentally ill young people in the beginning stages of our relationship with them.

Watching the reactions of seasoned mental health professionals as new cases are assigned to them provides some interesting insights into how well equipped our system is to deal with various types of clients.

These days, when a case management team hears that a new client is in the eighteen to twenty-five age range a collective groan often arises in the room. This is the same groan that has emerged for years upon learning that a new client suffered from Borderline Personality Disorder. Later it was the "Dual Diagnosis client", i.e. people with both mental health problems and chemical abuse issues, that evoked this negative reaction. The groan is a useful barometer of how much difficulty we expect to have in serving any particular group of clients. But why should we now be groaning just because a new client falls into the category of "young adult"?

One reason that we're having trouble serving these young people is simply that we are seeing a lot more of them these days. Why that should be true is a crucially important question for our society. If we are changing in ways that increase the likelihood that our children will have a mental illness we surely want to know what is going on. But our society has changed so fast and in so many ways that we're at a stage where clear cause and effect relationships are elusive.

A number of the other factors that make young adults problematic for our mental health programs are more straightforward.

#### Still holding onto their dreams

As terrible as this is to say, a significant "problem" in the mentally ill young adult population is that they have not yet given up their dreams for the future. It's natural for people to become angry when they're asked to face up to the fact that their life is not going to turn out in the way that they had imagined. And a lot of these kids coming into are system are, indeed, bitter and angry. One day they are dreaming of going to college, or becoming a successful businessperson, or a famous musician. Then the next thing they know someone that they barely know is trying to convince them to go to a day treatment program or drop-in center with chronically ill older adults. Who wouldn't be a little steamed?



"Tve never seen Mom this angry before."

Of course their parents are often pretty angry too. Our society as a whole has become less and less interested in personal responsibility these days. Some parents essentially hold the schools responsible for their children from the preschool years on. Responsible for educating the kids, but also for socializing them and teaching them how to live. So when children have left the educational system there has to be someone else that becomes responsible for them. And that burden often falls on the mental health system.



Our system routinely receives kids that have had serious problems for a decade or longer. Some of them have lived in a number of group homes or done time in Juvenile Corrections. In many cases nothing has really worked well for these young adults that must now be referred into the Adult Mental Health System on their 18<sup>th</sup> birthdays. Then, when we don't have decent services in place to care for them or when they don't thrive under our care, the families get justifiably angry.

Some version of "what is wrong with you people?" gets played out everywhere when these young adults don't do well. And no matter how often the mental health professionals have heard the question, or how much we insist that it isn't our fault, the question still carries a sting.

#### Rebellious kids in a system that values passive acceptance

It's no surprise that many of these young adults come into our adult mental health system with a prominent rebellious streak. Rebellion is part of the job of being a teenager. As distressing as it can be for parents to deal with, without that rebelliousness children might never leave the family home to start their own lives. And that would be distressing too.



In truth, most humans secretly value the rebellious side of themselves. We take pride in remembering how we wouldn't take anything that grown-ups said at face value. In recalling how no one could push us around. But it feels very different when it is *us* that's being rebelled against. When every word that comes out of our mouths is greeted with a disdainful sneer. When every helpful suggestion is rejected before it clears our lips. We mental health professionals are like anyone else. We like to be appreciated and admired. And these distressed young adults don't offer up much of that.

While it's hard to admit, we who care for the mentally ill often prefer our clients to passively accept our suggestions about how they should live their lives. The "good patient" is the one who does as we say, whether that means taking medications regularly or attending therapy groups or whatever. We're quick to brand any resistance or opposition to our plans for their lives as evidence of increased symptoms or "character disorder". So the older and more experienced patients frequently play a peculiar game with us. They pretend to welcome our ideas. "Sure Doc, that day treatment program might be just what I need". Or "I probably do need a third antipsychotic medication - I'll be sure to take it religiously - thanks so much".

But, of course, many have no intention whatsoever of actually doing the things that we suggest. They have simply learned that it's easier to deal with authority figures by seeming to be agreeable than by directly opposing us. Direct opposition can bring all sorts of painful consequences, from hospitalization to loss of one's apartment or financial subsidies to enforced chemical dependency treatment. But a lot of these young adults haven't learned the rules yet. So that groan emerges when they arrive.

#### Our existing programs are poorly equipped to serve young adults

Mental health professionals can handle just about any sort of client as long as we're confident that we'll have a good program to refer them to. The groans in response to "Borderline Personality Disorder" or "MI/CD" client have diminished as decent programs have been set up to help them. But our mental health system has not done well in creating specialized programs for mentally ill young people.

A common sequence when young people leave the family home involves first living in dormitories or other semi-independent settings. In dormitory life pretty much everything is provided and predictable. "Resident Advisors" or other older students provide some of the supervisory functions that previously fell upon parents. Not a lot of independent decision making is demanded of the freshmen. Then the student comes home on summer vacation, weekends, and holidays. So they're allowed to leave the nest gradually. And when a move to an apartment occurs it's typically with friends, so a little support system is available to replace the reliance on family. Unfortunately, this is rarely how things work out for the mentally ill.

Our mental health system in Minnesota still holds up living in mainstream apartments as the goal for every mentally ill client. But think about it. How many of us supposedly healthy adults would have been capable of managing an apartment at 18? Planning, making good decisions, accepting personal responsibility for one's own life - these are difficult tasks for any human. It would be a very mature 18 year old that could accomplish them. And those are certainly not the kids that are being referred for adult mental health services on their 18th birthdays.

So we often have to look to our group homes for mentally ill adults as our first housing option. But right away some predictable problems crop up. In almost all of our group homes one has to share a room with one or more other mentally ill people. Many of the existing clients are older and institutionalized. Some live from one cigarette to the next. These are boring places to live and they have a lot of rules. We put kids into them at a time when they have a lot of energy and are craving some sort of excitement. So it's rare to see an 18 to 20 year old kid make a successful long term adjustment to group home living.

For many young people "Basement Syndrome" is a real attraction. Living with their parents, in the basement, attic, or - preferably - their childhood bedroom is as good as it gets. They have often been forced out of the nest at the very time that their nervous system begins to fail them. A time when thinking clearly, making good decisions, and caring for themselves become extremely difficult. So it's natural that they'd want to get back to the last place they were when things were working OK. And that place is their parent's home.

A lot of parents are forced to endure sheer hell. They love their children. They don't want them to be homeless or living in shelters or existing in crowded group homes. But they

have encountered all sorts of problems with the mentally ill young adult in the past and have little reason to expect that things will be different now. The young patient tries to bargain their way back through the door. All sorts of promises are made. The kids swear that they'll get a job and start taking their medications regularly. They promise to go to their psychiatric appointments and stop smoking pot. They'll quit lying around all day and stop with the staying up all night. They'll be more respectful of their parents and their rules. But pretty soon the whole cycle begins anew.

Medications are stopped and symptoms start to recur. Jobs and structured activities fall by the wayside. Arguments and accusations resume. Eventually the kid is evicted from the house, often by way of hospitalization. Parents refuse to take them back. Short stays in group homes and shelters follow. And the promises begin again.

On the rare occasions when extended living with the family does work out the outcomes are often unsatisfactory too. We sometimes encounter parents who are in their eighties and are becoming increasingly concerned about what will happen to their mentally ill "child" when they pass on. Some of these patients are so dependent on their families that they cannot do the simplest things for themselves. One man in his late 50's had never brushed his own teeth, cooked a meal for himself, or washed his own clothes. So the issue of emancipation can be postponed but it must always be faced at some time. And there is always the matter of the parents wanting to have a decent life of their own. Many feel incredibly guilty about wanting something so basic for themselves.

### We have so little to offer these young adults...

As important as the problems with housing are, they are just a small part of the problems that we face in supporting these mentally ill young people. Think of some of the other routine parts of life that can become impossible for these kids to negotiate once mental illness sets in.



Few things are more important to young people than fitting in with a group of friends. These social groupings allow them to try out new identities, use different ways of relating to people, and are essential to the process of separating from parents. But the onset of mental illness commonly disrupts all existing relationships. Social skills and the ability to relate to others suffer. The clients may be experienced as being odd, unpredictable, labile, needy, or even "crazy". Previous friends often begin to distance themselves. Many are busy forming new relationships anyway. So the clients' tendency to isolate themselves becomes even greater.

Those that are "fortunate" enough to be placed in apartments may go for days on end without any contact with humans except the professionals that visit for an hour or two per week. We may suggest that they attend drop- in centers but those are typically open for just a few afternoon hours per weekday here in Minnesota. And attending them is dependent upon the young adult's self-identification as being mentally ill. That awareness of illness is often absent in adults who have been ill for decades. It's no surprise that many young people don't believe that they have an illness and strenuously resist any attempt to get them to accept a diagnostic label.



Of course sexual relationships are of particular importance to young adult humans. If memory serves, it can seem like that is all that they think about. But willingly accepting one's place in the mental health system can essentially mean giving up on the prospect of healthy sexual relationships.

Trying to become sexually active in a psychiatric facility of any kind is a difficult proposition. Even if someone could persuade a willing partner to return to their group home or treatment center the results would likely be unsatisfactory.

Prospective dates are rarely impressed with group homes for the mentally ill. And staff members will actively discourage their residents from engaging in sexual behaviors on the premises. The favorite term among mental health professionals - "that behavior is inappropriate"- is almost certain to be invoked. Privileges can be lost. Chart notes are entered. The client can feel that there are no acceptable outlets for their sexuality at a time when drives are very powerful.

Prospects are sometimes a little better for the clients that are trying to live alone. But not much. They may still have those problems with extreme self-consciousness or even self-loathing. Social skills may be very clumsy. And our mentally ill people typically live in poverty regardless of their age so dating in any conventional sense is out of the question.

Having access to an automobile is of extreme practical and symbolic importance to young people. It signifies that one is a functional adult. Relationships and employment are at least a little easier to negotiate if one is mobile. But having a car is another basic dream that we ask our young clients to surrender when they enter our system. With the exception of the lucky few who are subsidized by their parents, young people with mental illnesses can anticipate going their entire lives without a car.

Jobs are another vital source of identity for young people. Having a regular income is essential if one is to acquire all of the other trappings of adulthood. Working a regular forty hour workweek when one is struggling with symptoms of a severe mental illness is dramatically harder than most people realize. Sleep may be terribly disrupted. Attention and concentration are limited. Moods can change with little warning. Voices, visions, and paranoid thoughts can make focusing on external reality nearly impossible. "*Negative Symptoms*" of schizophrenia may sap the individual of energy, will, ambition, or a sense of future. The side effects of large amounts of tranquilizing medications can further compound problems.

Ironically, the importance of work for mentally ill people is readily accepted by most administrators and policy makers. But a real understanding of what life is like for these clients is often lacking and bad policy decisions are a common result despite good intentions

In recent years the emphasis has been on eliminating "supportive employment" for the mentally ill. Specialized "workshops" for the mentally ill have been done away with. The underlying assumption is that everyone can and should work competitively. We try to use vocational counselors or job coaches to help these folks to enter the work force. Sometimes this works well and when it does the importance of a good job to one's quality of life and self-esteem become quite apparent. But we're seeing a lot of people that simply don't fit into the master plan to involve them in mainstream jobs. So a pattern of failed expectations, demoralization, and an eventual surrender of vocational goals is an all too common result.

Most mental health professionals have known countless clients of all ages who declare themselves "retired" from the workforce, despite never having worked for more than a few months at a time during their adult lives. And many more clients still want very much to work but cannot find a setting that allows them a reasonable chance of success.

Ironically, since the few specialized work settings for the mentally ill have been eliminated by people who aim to encourage greater independence for them, we've seen a gradual return of these clients to the even more structured workshops geared for the mentally retarded. It is not atypical for these work programs to charge government agencies over \$200 per day to have a mentally ill client spend several hours doing piecework, making a wage of two to three dollars per hour. Obviously, this runs counter to common sense and highlights some serious flaws in our system.



Having families of their own is something else that most young adults assume is in their future. But most of our clients in the adult mental health system don't manage to accomplish this either. Marriages are typically short-lived and stormy when they do occur. Sometimes young mentally ill people try desperately to grab at the trappings of adulthood, as though they are aware that their shot may never come again. They'll pair up, have a child, and try to make a go of it in an apartment. But all too frequently they are not up to the task. Losing custody of one's children is extremely common among mentally ill people. Parenthood just becomes something else that they've failed at and the relationships with children that they never see are another source of guilt and self-recrimination.

#### Everyone needs a sense of control

The issue of substance abuse can become enormously important in the lives of any young adult but quickly coming to the position that they can and should be abstinent from mood-altering chemicals for the rest of their days doesn't always yield satisfactory results. Everyone is different. And it's not like the rest of society's adults will be behaving in similar fashion.

Sometimes kids use drugs because it feels like one of the few areas that they have any control over. It reminds them - and the professionals around them- whose life is really involved here. Using drugs or alcohol - often quite openly - serves as a direct expression of their rebellious feelings.



Just think of the things that young people can lose control of when they enter our mental health system. Their income typically becomes dependent on their disability benefits. They must rely on others to determine whether they will receive money, and in what amount. All of the things that money stands for in our society, including power and status, may be out of their reach.

We professionals usually determine whether they will have access to supported employment. We tell them where they will be able to live. Group homes have curfews so we tell them when they can come and go. We prohibit them from bringing people back to their rooms. We may control access to transportation. We tell them what psychiatrist or therapy program to use. If they are to get into any educational or vocational training programs they must go through us. We may even control what they eat.

A sense of control is vitally important to humans of any age. Studies have even shown that newborn babies will control exert control in their relationships by deciding what they and their parents will look at together. If eye movement is all that they can utilize then that's what they'll use. Later, control issues get played out over what will go into their bodies and when or where it will come out. Humans struggle for control using whatever tactics are available to them.

We mental health professionals sometimes forget how important control is to our clients. Our relationships with them can quickly degenerate into a battle for control over what substances they will or will not take into their bodies. Fighting on that battleground is a

doomed proposition right from the start. It's a struggle that we cannot possibly "win". And even if we could have and maintain that degree of control over these people's lives would we really want that?

## What do we really provide for these young adults?

So a pessimistic view of the mental health system would hold that we do a fair to poor job of giving these young adults a fighting chance at obtaining good housing, meaningful work, adequate access to transportation, or opportunities for satisfying relationships. All of us can point to far too many mentally ill adults who have never owned a car, never held a regular job, never had stable or satisfactory housing, and have never been involved in a sexual relationship.

A good question becomes "What exactly do we offer these young people?"

Unfortunately, the answer is usually "The same things that we offer older adults with mental illness but for a longer time".

We in the mental health system are very prone to scrutinizing people. Visits with us can feel like a microscopic examination aimed at discovering every little flaw. We often overlook how painful this scrutiny can be for mentally ill people that are already terribly self- conscious. Sad to say, much of our scrutinizing is ultimately based in self interest.

We want our clients to reflect well on us. We want them to have goals and show progress and attend treatment programs regularly. We particularly don't want them to misbehave in ways that we can be blamed for. So there is a broad tendency to label any anger or irritability as evidence of symptoms of the underlying illness, with a resultant push for more medication to control the symptoms. Talk to any group of mentally ill consumers and the complaint that "I can never get angry for any reason without someone asking me if I'm taking my medications" is likely to emerge. And, of course, mentally ill people often have a lot of perfectly good reasons to be angry.

One would hope that all of the scrutinizing that we engage in would at least lead to accurate and reliable diagnoses. But, unfortunately, we offer these young adults the same hodgepodge of shifting diagnoses, with a pronounced tendency to eventually call them "schizoaffective", that we offer everyone else. In fact making an accurate diagnosis in young people is even more fraught with error than in other populations.



"Oh no, not dinner again!"

Mental illnesses often have to be given time to "declare themselves". Good long term data are needed to make reliable diagnoses or provide a meaningful prognosis. Many of these kids just haven't been ill long enough to have that sort of track record to go on. And separating out behaviors, problems, and attitudes that are attributable to mental illness from those that commonly arise in *anyone's* teenage years can be difficult indeed.

Of course, long-term relationships with well-trained and caring psychiatrists are important for mentally ill young people. But our system offers them something rather different. Fifteen minute appointments every three to six months are becoming commonplace for everyone. This prevailing model does not lend itself to the formation of solid, trusting relationships or meaningful therapeutic alliances. So young people and their families must often lower their ideas of what good psychiatric care should look like.

Sadly, our society can still offer these newly ill young people the expectation that they will be subjected to the stigma associated with mental illness wherever they go in life. We can statistically predict that there is a greater chance of a mentally ill person ending up in a prison or homeless shelter than in a decent living environment that meets the needs of their illness. And we can also reliably predict that a great many people in our society will assume that these young clients just didn't try hard enough or are in these dire circumstances as a result of their own poor choices or laziness. Prejudices, fears, and distortions change slowly when they change at all.

So to say that young people don't really have a lot to look forward to when they enter the adult mental health system is a bit of an understatement. This is not to say that successes

never occur. There are a lot of wonderful professionals out there that help young people every day, despite whatever programmatic or funding limitations they might be dealing with. Some psychiatrists manage to connect with people in ways that go beyond the brief visits for pills. Innovative housing and support programs for young adults are beginning to crop up occasionally. The glass can look half full from the right perspective. But anyone looking for instances where the mental health system has failed young people miserably doesn't have to look too far or too hard. And that groan that occurs when we hear that a new client is a "young adult" is pretty easy to understand after all.

## What can we do to address a growing problem of this magnitude?

How can we effectively serve a growing number of young clients, especially when so many have multiple problems and budgets for programs to address them are shrinking? The first question that we need to keep asking is "what would an ideal system of care for mentally ill young adults look like?"

In an ideal system we'd prioritize how we'd spend the available dollars. Providing our clients with decent housing options, good diets, and reliable access to needed medications and supports should be taken care of first. Without these basics nothing else that we do to help these kids will have much chance of success.

Symmetrical, respectful relationships with caregivers - relationships that recognize both the rights and responsibilities of the client - should also be cornerstones of our evolving mental health system.

Housing and support programs should be tailored to the actual neurological deficits that the clients have to deal with. Basic biological needs such as control over one's exposure to other humans must be met. Either too little privacy or inadequate human contact can be difficult for nervous systems to deal with. Access to stimulating activities, exercise, laughter, and freedom from excessive stressors should be available in whatever programs we create.

Homes that are specifically designed to meet the client's needs might end up looking a bit like college dormitories. Throw in a dash of youth hostel and some elements from the "therapeutic communities" that have existed in psychiatric hospitals and we just might be able to provide long term housing that these clients will *want* to stay in - and that will allow their parents to sleep at night too.

An ideal system would provide clients with real help in finding and maintaining meaningful employment. That should be a genuine priority. Teaching them usable job skills and helping them to find employment that matches up well with the strengths and weaknesses of their nervous systems only makes sense if our goal is to help these kids to be productive citizens in their later years.

Focusing on education will be cost-effective in the long run. Better programs to teach the

clients about the true nature of their illnesses and how to best manage them will be essential if clients are going to take real steps towards recovery. Recovery doesn't truly begin until the client begins to "own" their mental illness and actively participate in its management. Education should also take other forms, including connections with GED classes, local universities, and having the opportunity to take some courses simply because they're interesting. Learning just about anything is good for the brain and for the self-esteem of its owner.

A lot of simple things can be done to upgrade the medication treatment that these young people will receive during their lifetimes. Using the basic strategies supported by Evidence Based Treatment before exposing them to high dose treatment or experimental combinations only makes sense. Careful medication trials of adequate duration and a systematic way to track the results of these trials will go a long way towards reducing some of the mistakes that we've made with generations of previous clients. We should always use good generic medications when they are available, especially when the costly brand name drugs are not offering substantial advantages.



"Im sorry, the doctor no longer makes diagnoses."

Since very few of these young people will have long enough psychiatric histories to conclude with absolute certainty that they'll have to be taking medications "for the rest of their lives" we might want to prepare for the possibility that some will want to find out for themselves whether these drugs are essential to their functioning. Helping them to address the issue in a way that truly provides them with the best chance of living without medications will go a long way to reducing futile power struggles around taking medications.

If they do insist on stopping their meds we should provide direction, support, and even let them know that we're rooting for them. Should it turn out that medications are necessary, the relationships that support that kind of treatment will be better for having respected their right to choose. Peer support and having an environment that won't automatically exclude them if they guess wrong about needing drug treatment will help to make the whole issue less pressurized than it currently is too.

In an ideal system we'd have to rethink the way we respond when these young clients use the other kinds of drugs. Perhaps we'd be willing to learn from other societies that do a better job of dealing with this issue. Other countries don't try to pretend that every client is going to abstain from alcohol and drugs throughout their adult lives or that all drug use is of the same severity. It's possible to be relatively tolerant of alcohol and marijuanamaintaining a focus on the real consequences of the use in the individual's life- and still take a very hard line on hard drugs like cocaine, methamphetamine, and opiates. Our society doesn't treat these drugs as if they pose the same dangers so there's no reason why our mental health systems should behave that way.

Anything that we can do to make our programs as financially self-sustaining as possible will go a long way towards allowing us to serve more people with our limited budgets.

Whenever work can be done by the clients themselves that should be encouraged. We should provide meaningful rewards for even small steps towards more independent functioning. At the same time we need to systematically examine our system to seek out and eliminate areas in which we provide actual incentives for clients to do less for themselves than they are able to. As has been stressed elsewhere, our difficulties in providing realistic incentives to becoming more functional - and eliminating the incentives to remain dependent - are some of the most important and widespread weaknesses in our present mental health system.

#### Investing in our future

Let's face it. A great many people in our society won't care much about the fate of our mentally ill young adults unless their own lives are touched by the issue. No one wants to pay out more of their income for increased taxes or more comprehensive social programs. But it is clearly in all of our best interests to find a better way of addressing the mounting problems that our society is now facing.

If we can find effective and efficient ways to provide decent lives for young people with mental illness it will benefit us all. Their long-term costs for hospital treatment, incarceration, and welfare programs will decrease. More will become productive citizens and pay taxes themselves. The burden that is so often shouldered by family members may lessen a bit too.

Ultimately, it's likely to be the effects on family members that will drive the changes that our mental health system so desperately needs. As mental illness rates in our society continue to climb it will become increasing difficult to write off mental illness as

something that only happens to someone else's family - or to people that somehow deserve their fate. When stigma, ignorance, and superstition fade away there will be plenty of room created for common sense, understanding, and kindness.

Once we've adequately addressed the question of what an ideal system of care for these mentally ill young adults should look like, the second one becomes a lot easier. That, of course, is "how would we want *our own* children treated should they develop a severe mental illness?" How many of us would willingly accept a significant downgrade from the ideal?