



This Toolkit is one of a two-part series. The companion Toolkit is geared towards students and families.

## Back to School: Toolkits to Support the Full Inclusion of Students with Early Psychosis in Higher Education

### CAMPUS STAFF & ADMINISTRATOR VERSION

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# 1

## Introduction & Orientation

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### THE BACK TO SCHOOL TOOLKITS

Over the past decade, interest and investment in specialty early intervention in psychosis (EIP) programs has greatly expanded across the United States, fueled in part by dedicated federal funding mechanisms, such as the Substance Abuse and Mental Health Services Administration (SAMHSA) Community Mental Health Block Grant set-aside for first episode psychosis services, and research support from the National Institute of Mental Health (NIMH).

A major goal of EIP services is the functional recovery and community integration of emerging adults with first episode psychosis. Many programs include dedicated supported education or vocational rehabilitation components. The recent (exponential) growth of such services means that many more young Americans will be encouraged and supported to enroll in institutions of higher education, including city and community colleges, four year universities, and graduate and professional programs. The Back to School Toolkits are designed to help support the integration and inclusion of such students.

Many different stakeholders play important roles in campus life. For this reason, the Toolkits include both components that target specific groups (such as campus disability support services staff, administrators, counseling center staff, parents and students) and some materials intended for a cross-stakeholder audience. Two separate Toolkits are available: one targets students and families, the other campus administrators, staff and other members of the campus community such as student advocates. Both Toolkits include information briefs and handouts designed to be re-posted or printed and disseminated on college campuses. Components relevant to both broad groups are replicated in each Toolkit.

The Back to School Toolkit was developed and reviewed by a team including: current and former students with personal experience of early psychosis while in college; family members and specialty early intervention in psychosis (EIP) program clinicians and staff; and a campus mental health attorney.



# 2

## Introduction & Orientation for Campus Administrators, Faculty & Staff

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### INTRODUCTION

Depending on your role and responsibilities, you might be wondering why guidance materials aimed at supporting students with early psychosis have been created or, conversely, why it's taken the field so long to recognize the need for guidance. The number of students perceived as having more serious psychiatric challenges and diagnoses has been steadily increasing for the past decade and a half, although no one is sure exactly why. Recent federal initiatives aimed at providing effective, high quality wraparound early intervention services to young people experiencing a first episode of psychosis are likely to further contribute to the number of postsecondary students with psychosis. In fact, increasing the college attainment of clients is an explicit goal of most early intervention programs.

## Orientation

The goal of this orientation is to introduce and explore a handful of big-picture issues. Other modules in the Back to School Toolkit resource series address such topics as the psychosis-violence intersection, and policy recommendations for strengthening campus services and supporting students with psychosis. This section covers:

- [What “psychosis” means](#)
- [Academic impacts](#)
- [Background on early intervention in psychosis \(EIP\)](#)
- [Campus – early intervention linkages](#)

## What is “Psychosis”?

“Psychosis” is generally defined as a set of related symptoms involving a break with reality (for instance, hearing voices or believing things are happening that in fact aren’t). Many specific diagnoses involve psychosis, including schizophrenia, schizoaffective disorder, schizophreniform disorder, bipolar disorder with psychotic features, and depression with psychotic features. Certain individual symptoms associated with psychosis, such as hearing voices, can also be present in anxiety disorders, Post-Traumatic Stress Disorder (PTSD), and complicated grief.



Trajectories following a first episode of psychosis can be highly variable. For example, some young people may experience just one or two episodes and then never experience psychosis again for the rest of their lives, even without further treatment. Others may develop chronic but manageable symptoms, while a further sub-group tends to experience a much more severe course, with significant disability and symptoms that are difficult to manage even with the best available supports. In general, however, effective early intervention significantly improves functioning and reduces the risk of long-term disability and more severe symptoms.

### COMMON SYMPTOMS ASSOCIATED WITH PSYCHOSIS INCLUDE:

- **Voices or auditory hallucinations:** individuals may hear multiple voices or just a single voice, and their communications can be simple or complex, abusive, neutral or soothing;
- **Tactile or somatic sensations or hallucinations:** strange bodily sensations or feelings, sometimes described as “electric” charges, or the feeling of very small bugs crawling over a leg or arm;
- **Paranoia and feelings of persecution:** the often intense sense that someone is after the individual, that he or she is being following, persecuted or has been put under surveillance; that people are talking about, looking at or laughing at the individual;
- **Derealization:** the world may feel strongly false or unreal, or the individual may feel as if certain people or objects are fake or are not who or what they superficially appear to be;
- **Cognitive disorganization:** speech and writing may become very disorganized and/or tangential; individuals may jump from topic to topic, draw connections between words or terms that do not make sense to others, or have trouble following conversations;
- **Slowing of speech and movement:** it may be difficult to speak, or difficult to initiate speech, and individuals with psychosis may move more slowly and have a difficult time mustering the energy to do things;
- **Depression and demoralization:** many individuals with psychosis experience significant depression and/or demoralization stemming from their challenges, perceived loss of goals and dreams, and/or societal reactions.

Always keep in mind that any given student with psychosis may experience all, or only a few, of the above symptoms. The intensity and impact of particular symptoms can also vary enormously from individual to individual.

## Academic Impacts

As is true of specific symptoms, the academic impact of psychosis can vary considerably from student to student. Some individuals with a very high level of academic accomplishment prior to developing psychosis, may be able to weather their symptoms with relatively little impact on school performance. Others will find themselves much more significantly affected. Specific impacts are covered in more detail in the accommodations guidance factsheets and modules in [Sections 4, 5 and 6](#) of this Toolkit. It is always important to remember that, like students with a variety of other disabilities, students with psychosis can thrive with the right resources and supports: see the [Voices of Success factsheet for proof](#).

## Background on Early Intervention in Psychosis Programs

As mentioned in the introductory section, several federal initiatives have helped to support the development of specialty early intervention in psychosis (EIP) programs across the United States (also frequently referred to as “coordinated specialty care” or CSC). These initiatives

include the NIMH’s [Recovery After an Initial Schizophrenia Episode \(RAISE\) initiative](#), President Obama’s [Now Is The Time \(NITT\) initiative](#), focused on increasing mental health services access for youth and young adults, and the [10% set-aside](#) associated with the SAMHSA community mental health block grant (MHBG) program. The set-aside requires each state to utilize 10% of its federal MHBG funds to support services and programs designed to address the needs of persons experiencing a first episode of psychosis.

EIP programs explicitly aim to intervene as quickly and effectively as possible following a first episode of psychosis, to minimize disruptions to life trajectories, and support ‘functional recovery’ or the individual’s ability to meet normative school, work and relationship milestones. Most programs include explicit ‘supported education’ components, typically including dedicated vocational

rehabilitation specialists. A major goal of such components is to support clients’ educational advancement, including starting or returning to college. Many EIP programs have reported robust postsecondary enrollment rates for clients.



## Campus – Early Intervention Program Linkages

Unlike many more conventional mental health programs, specialized EIP programs often include explicit supported education components as well as outreach and partnerships with local schools and other institutions. These features create potentially rich opportunities for more extended partnership.

We encourage university administrators to consider possibilities for partnership, reach out to EIP programs and also ensure that key staff and administration officials are aware of local services. Additional recommendations and suggestions for collaboration are included in the [Increasing Early Psychosis Awareness and Strengthening Campus Supports](#) module within this toolkit. A few examples include:

- Working with EIP programs to provide **on-campus early detection, awareness, stigma reduction or social support events or workshops**;
- Working with EIP programs to provide **on-campus supports specific to students with psychosis** and/or establishing formal academic support programming;
- **Involving EIP program staff in the planning and/or implementation of campus emergency and/or threat assessment protocols** focused on mental health-related emergencies and/or threats;
- **More ambitious partnerships**, such as co-developing a mentoring program for students with early psychosis or on-campus support groups led by EIP program staff.

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## Summary

Significant federal investments in early psychosis and early intervention have created a historically unprecedented opportunity for postsecondary institutions to partner with clinical programs and leverage funds and political capital to raise the bar on campus supports for students with significant psychiatric disabilities and help ensure that today's students are better positioned to assume leadership positions within policy, academia and other professional paths and careers.





# 3

## Recognizing Signs and Effectively Engaging Students with Early Psychosis: An Information Brief for Campus Counseling Staff

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Over the last few decades, the number of students with significant psychiatric disabilities in postsecondary settings has been steadily rising, including students with recent onset psychosis. Instructors and campus staff, including counselors and clinicians, are often among the first providers to come in contact with students who are experiencing early signs and symptoms of a psychotic disorder. Because early psychosis can (and often does) look different from more chronic manifestations, it often goes undetected, delaying entry into quality treatment. This information brief is designed to help clinical staff recognize and effectively engage with students experiencing early symptoms.

### THE IMPORTANCE OF EARLY DETECTION

A recent study of clients served by community mental health centers in the United States found that the average duration of untreated psychosis—the time between the onset of psychotic symptoms and treatment—was 74 weeks (nearly a year and a half).<sup>1</sup> This statistic is particularly unsettling given what we know about the long-term impact of treatment delays: regardless of what services are subsequently provided, longer duration of untreated psychosis has been linked to worse outcomes in terms of both symptoms and functioning years or decades down the road.<sup>2</sup> *At the same time, it bears remembering that inaccurate accusations or assumptions of psychosis can be extremely damaging to the student and hence extreme care should always be taken in the context of initial assessment and engagement.*

## INDICATIONS OF EARLY PSYCHOSIS

The earliest signs and symptoms of psychosis can be significantly more difficult to recognize than established psychosis. This may be particularly true for young people



whose symptoms slowly creep up on them, rather than manifesting in a more obvious and acute psychotic break. In addition, because of all the normal challenges of college life, students experiencing early psychosis—as well as their friends and family members—may not recognize the nature of the changes they are experiencing and instead view them as expected reactions to common college experiences such as sleep deprivation, recreational drug use, or stress stemming from final exams. In addition, signs and symptoms of early psychosis may come and go, confusing friends and campus staff who might see what appear to be signs of obvious problems one week that vanish the next. Additionally, many mental illnesses can have psychotic features, making diagnosis difficult.

### Clinical Signs & Symptoms

- **Distinct but confusing alterations of perception and sensation.** These might include sporadic, transient or only quasi-hallucinatory “voices,” changes in depth perception (feeling like objects are closer or farther away), or perceptual disorientation. More obvious signs like clear auditory hallucinations and/or somatic or tactile hallucinations may also be present.
- **Feelings of unreality and/or derealization:** Individuals with early psychosis often report feeling like the world suddenly feels “wrong,” “fake,” or “unreal,” even though they may not be able to articulate why. For instance, a student might report that there is something “off” about other people’s faces, but not be able to explain exactly what’s wrong or changed.
- **Preoccupation with particular themes or ideas:** Individuals may become particularly focused on certain themes or ideas: often philosophical, religious/spiritual, or political. Compared to past interests, these preoccupations are typically much more obsessive or all-consuming and may negatively impact social relationships.

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“It’s very difficult to describe the changes I started to experience, but overall everything suddenly felt very different... The world looked different, my hands felt different, I felt confused by my own thoughts and had much more trouble following what professors were saying in class. But nothing obvious like hallucinations... When I first told a campus counselor about this, she said I probably just needed more sleep. If she had connected the dots, I would have gotten help about 6 months sooner.”

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- **Attenuated ego boundaries:** Individuals with early psychosis may feel that they are suddenly less in control of their own thoughts and actions, or that they are being controlled or manipulated by others. They might find it difficult to distinguish between their thoughts and others' thoughts, or between their thoughts and what others are saying out loud.
- **Paranoia & feelings of persecution:** Early paranoia can range from transient or subtle concerns about being watched or followed, to beliefs that others are talking or whispering about an individual or are actively pursuing him/her.
- **Unusual salience:** Sensations, including tastes, smells, and colors, may suddenly seem more pronounced or differentiated. A student might report paying more attention to small details, or even getting so "stuck" on small details that it's difficult to re-orient to the bigger picture. People, words and objects may seem more meaning-laden than before or connected in ways the student had not previously realized. In general, these "connections" will most often sound like random coincidences or non-meaningful relationships to others.
- **Changes in language processing.** While a student may not know how to describe exactly what is going on, he or she may report sudden difficulties reading, writing or following what other people are saying. In many cases such changes will interfere with academic work, making it more difficult to complete tasks that the student previously had no problem with.

### Behavioral Indicators

Social withdrawal or self-isolation;

Sudden decline in grades or school performance;

Expressions of extreme fear, including sudden reluctance to attend specific events or leave a dorm-room or apartment;

Uncharacteristic and seemingly odd or bizarre actions or statements, including sudden aggressiveness or secrecy that cannot otherwise be accounted for;

Sudden and pronounced obsession or preoccupation with narrow themes or topics, reflected in student's academic work;

Clear changes in sleep patterns, personal hygiene, or eating habits;

Over-dressing (i.e. wearing cold-weather clothes or multiple layers, in warm or hot weather); and

Difficulty getting to or staying in class, doing homework, completing assignments.

## EFFECTIVELY ENGAGING WITH STUDENTS POTENTIALLY EXPERIENCING EARLY SIGNS & SYMPTOMS

In many cases, students exhibiting early signs or symptoms and who have never previously received treatment for psychosis, will be unlikely to conceptualize their experiences as ‘mental illness’ (or identify with specific clinical terms such as ‘hallucinations’ or ‘delusions’). Subtle feelings of paranoia may further complicate initial engagement, making it difficult for clinicians to establish rapport and persuade the student that they are trustworthy. In other cases, a student may actually be hearing voices that directly instruct them not to trust anyone, or not to say anything. Given these considerations, we recommend a “soft” approach to initial engagement, in line with the following tenets:

- **Lead off with broad, open-ended questions** such as “tell me what’s been going on” and then ask follow-up questions that use the student’s own language and terminology. For example, if student tells you that she’s developed a “super-sensitivity” to what other people are saying, don’t follow up with a question about whether or not these are voices or hallucinations, but instead ask her how this new sensitivity developed, what sorts of things she hears others saying, and how it is impacting her. Other potential lead off questions include: “has this happened before?”; “have you been talking with anyone else about this?”.
- **Normalize unusual experiences:** tell the student that college students often have unusual experiences, often stemming from sleep deprivation, recreational drug use, break-ups, and/or test-related stress and performance anxiety. The goal is to help him or her feel more comfortable and less “weird” or “crazy” for sharing his or her experiences with you.

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“I’d already heard rumors from friends about the counseling staff calling campus security and having people hauled off to the ER after just an initial consultation, so I was scared already. Then I walked in and the director started the conversations by asking me if I thought people were following me or I was hearing voices. And I was like “okay, yeah, no way am I gonna tell this person anything;” it seemed clear what was going through her head.”

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- **Avoid potentially frightening terminology:** avoid using clinical language and asking the sorts of questions common in diagnostic assessments (for instance “are you hearing voices”). Rather than labelling, try to listen to whatever the student has to say.
- **Be as reassuring as possible:** For many people, the subjective experience of early psychosis is both terrifying and difficult to describe to others. Wherever possible, try to assure the student that he or she will be okay, and that your office or department will support him or her however possible.

- **Gently explore the possibility of contacting the student’s family without threatening him or her:** Try to find out if the student’s family (or significant others) already have some awareness of his or her struggles; if not, gently ask the student if communicating with them might be helpful. If the student says ‘no,’ don’t force the issue; the initial goal is to build trust and unless the situation is an emergency, you can always return to issues such as family involvement at a later point.
- **Proactively and honestly address common stereotypes about campus staff or campus counseling services.** For example, “you may have heard that campus counseling staff don’t have to respect federal laws concerning patient privacy; we do, except under the following circumstances” or “you may have heard that we regularly have students escorted to the ER by campus security; in fact...”

### RISK ASSESSMENT & SAFETY



If you have not previously worked with (or encountered) individuals experiencing psychosis, it may be frightening or alarming to do so for the first time. Even counseling staff with substantial experience working with other mental health issues (eating disorders, anxiety, depression), may find reports of symptoms associated with psychosis alarming. Persons experiencing early psychosis are more likely to experience suicidal thoughts than thoughts about harming others. *Always remember that very few young people with psychosis actually pose a risk of serious harm to others.* (See the [Psychosis & Violence: Just the Facts](#) information brief in this Toolkit for further information.) This does not mean that a particular individual might not pose a legitimate risk, however. When you have legitimate reasons for concern for the individual’s safety or the safety of others—for instance the student says his or her voices are telling him/her to kill themselves or someone else, *remember this does not mean the person will act on these thoughts*—however, check with a designated threat assessment team or team leader at your university as quickly as possible. If you feel uncomfortable, even if the student does not appear to represent any immediate risk, do what you can to help connect him/her with staff or campus clinicians in a position to effectively engage and monitor. The student may feel alone and frightened: be available to the student, be part of the safety net, if needed, let them know who and how to contact if they begin to feel unsafe.

### Additional Recommendations

- **If your college or university is unable to provide clinical or counseling services for students with psychotic disorders, be prepared to provide high quality referrals to outpatient treatment centers.** If possible, assist a student with appointment scheduling, working to ensure that he or she is able to schedule and attend an initial assessment.
- **Keep in mind that hospitalization is not always necessary and can be harmful: ideally, students with recent onset psychosis, wherever possible, would be served in outpatient settings** with minimal disruption to school and other activities and relationships. For many students, the structure that coursework and extracurriculars provide is grounding and therapeutic and the sudden loss of this structure can seriously exacerbate symptoms rather than alleviating them. Staff should always consider the necessity of hospitalization and the potential negative consequences.

- **If there are specialty early intervention in psychosis (EIP) programs in your region or state**, try to develop relationships with their staff and refer directly to such programs whenever possible.
- **Where applicable, attempt to identify associated students (e.g., friends, classmates, romantic partners or residential assistants/dorm leaders) who may themselves need support and/or psychoeducation.** Such students may also be experiencing significant distress and confusion, and have little context to understand what is going on. In addition, they may be an important source of support for the student experiencing early psychosis, so long as their own needs are met.

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## Summary

Optimal engagement with a person experiencing early psychosis centers on meeting a student where he or she is, avoiding heavy-handed clinical terminology or lines of questioning, and ensuring that the student feels as safe and comfortable as possible. While risks or threat may be present a small percent of time, the vast majority of young people with early psychosis pose absolutely no danger to others and are likely to be experiencing significant fear, anxiety or disorientation. Flexible, empathic engagement lays the foundation for successfully moving struggling young people into treatment and connecting them with the full range of supports they may need.

<sup>1</sup>Addington, J., Heinssen, R. K., Robinson, D. G., Schooler, N. R., Marcy, P., Brunette, M. F., ... & Robinson, J. A. (2015). Duration of untreated psychosis in community treatment settings in the United States. *Psychiatric Services*, 66(7), 753-756.

<sup>2</sup>Penttilä, M., Jääskeläinen, E., Hirvonen, N., Isohanni, M., & Miettunen, J. (2014). Duration of untreated psychosis as predictor of long-term outcome in schizophrenia: systematic review and meta-analysis. *The British Journal of Psychiatry*, 205(2), 88-94.

# 4

## Accommodating Students with Psychosis: An Information Brief for Campus Disability Services Staff

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Over the last few decades, the number of students with significant psychiatric disabilities in postsecondary settings has been steadily rising, including students with recent or first episode psychosis. The goal of this information brief is to provide targeted guidance on the symptoms and impact of psychosis, along with more general guidance on accommodations. The Toolkit also includes extended lists of specific potential accommodations for students with psychosis and the rationale behind them.

### **WHAT EXACTLY IS “PSYCHOSIS?”**

Psychosis is an umbrella term that refers to a set of related symptoms (including hallucinations and delusions) all thought to involve a “break with reality.” Diagnoses associated with psychosis include schizophrenia, schizoaffective disorder, schizophreniform disorder, psychosis NOS, bipolar disorder with psychotic features, and depression with psychotic features. Individuals with PTSD may also experience psychotic symptoms such as auditory hallucinations (voices).

### **CAN STUDENTS WITH PSYCHOSIS REALLY BE SUCCESSFUL?**

As is true for many other disabilities, psychosis can lead to multiple additional challenges and obstacles for students, but with the right resources and supports these can almost always be addressed. For more information on successful current or former students with psychosis, see the Toolkit’s Voices of Success Information Brief.

“Recovery”—doing well and pursuing important life goals—should be seen as the rule rather than the exception.”

### Common Symptoms Associated with Psychosis and/or Medications

- Mild to severe **paranoia**, often accompanied by social anxiety; paranoia can intensify during high stress periods (such as midterms or final exam periods) and under specific circumstances (important presentations, meetings with faculty or administrators). The student may feel like people or entities (such as the FBI) are after him or her, that he/she is being following or watched, or the individual may simply feel constantly fearful and afraid.
- **Voices (auditory hallucinations)** may be episodic or ongoing and can disrupt a student's ability to concentrate, track lectures, or complete reading assignments in the same amount of time it might take another student. For some individuals, voices can be exacerbated by group conversations, excessive background noise or anxiety-inducing situations, including test-taking and public speaking. Some individuals might experience voices more as non-auditory messages that can be very disruptive and completely outside their control, or one might hear multiple loud voices that disrupt the student's ability to follow or track actual conversations.
- **Disorganized thinking** can also make it difficult to follow lectures, track conversations, or complete reading assignments in the same amount of time the same material might take other students. A student might become excessively preoccupied with the multiple meanings of individual words, have difficulty reining in "free associations" while reading, or experience difficulty writing or communicating clearly.
- **Disorienting perceptual and/or interpersonal experiences:** individuals with early psychosis often experience multiple changes in both perception (including changes in depth perception and the way their body feels) and interpersonal experience (for instance, feeling like other people can read their thoughts or directly access what is going on in their mind).
- **Depression and anxiety** may occur secondary to psychosis, or instead kindle or trigger psychotic symptoms. Students with psychosis may have a difficult time with basic self-care and motivation, as well as low self-esteem and demoralization. Anxiety is often related to paranoia (and fears of persecution) and is often triggered by social situations in which the individual feels uncomfortable.
- **Cognitive difficulties** involving memory and attention are common. Psychosis is most often associated with working memory, episodic memory, limited attention span and compromised cognitive control.
- **Lethargy, extreme fatigue and mental cloudiness** are common side effects of medications used to treat psychosis. In some cases, fatigue may be so pronounced that students have a difficult time staying awake in class, and may need to sleep as much as 12 to 16 hours a day.





### Common Challenges and Barriers Stemming from Psychosis

- **Unpredictable Course and Impact.** Psychotic symptoms can disappear (or ‘go into remission’) for lengthy periods of time and then suddenly reappear without warning. They can also manifest under certain circumstances (e.g., a particular class) but not others (e.g., other classes the student is taking at the same time). A student with psychosis may think that accommodations are not needed for a particular class, but then 10 weeks into the course experience an intensification of symptoms and only then realize that an accommodation is indeed necessary.
- **Sudden & Unexpected Acute Episodes or Exacerbations.** Acute psychosis can lead to voluntary or involuntary hospitalizations, a sudden need to reduce course loads or even withdraw from classes, and the disruption of relationships with faculty, advisors and mentors, campus administrators and other students. Even after symptoms have resolved, a student returning to campus may feel intense shame and/or social anxiety that can make it difficult to resume courses and follow up with faculty and peers.
- **Interpersonal Challenges.** Stressful social encounters—such as approaching a faculty member to understand low marks on a paper or exam—can be extremely difficult for students experiencing voices, paranoia or associated social anxiety. Similarly, group assignments can be challenging even for students who are highly gifted academically. Certain personalities (for instance, a faculty member who appears more demanding or judgmental) may trigger particular symptoms, while others do not.
- **Academic Challenges.** Symptoms and medication side effects can impact more or less any academic task: reading, writing, speaking, working with numbers, memorizing information for tests, presenting and following lectures.
- **Environmental Challenges.** Students with psychosis may feel overwhelmed by excessive sensory stimuli (such as the noise in a large lecture hall, or by lighting that is unusually bright). Conversely, students experiencing medication-induced fatigue may find it difficult to stay alert for long periods of time, particularly in lecture-style courses that involve little interaction and/or infrequent breaks. Particular settings may also be ‘triggering’ for more personal and/or idiosyncratic reasons.

### THINKING OUTSIDE THE BOX DURING THE ACCOMMODATIONS PROCESS

For good reason, disability support services staff often rely on ready-to-go lists of common, relatively innocuous accommodations such as advance registration for courses or extended time on exams: such accommodations are widely used for multiple disability groups, are familiar to faculty and rarely require potentially lengthy and time-consuming discussions about what is or isn’t an “essential” element of a given class (or specific assignment). Unfortunately, there is little evidence that such generic accommodations effectively address the core challenges that students with psychosis typically face or that such accommodations meaningfully “level the playing field.” Common campus disability center requirements such as guidelines that require students to request specific accommodations weeks in advance of term start-dates make sense for more stable, predictable disabilities but create additional barriers for students whose symptoms are highly variable, unpredictable or in flux. Accordingly, this brief provides some general guidelines aimed at improving the quality of the accommodations approval process.

### Memory & Essential Elements: Thinking Critically

Disabilities (such as psychosis) that can significantly impact memory (both encoding and retrieving information) may create enormous challenges for students in courses and areas in which exams are often primarily tests of memory (for example, language and basic science classes). If we think about the skills and abilities actually needed to succeed as a professional scientist or translator, however, the status of (or need for) rote memorization is much more questionable.

#### What do you think?

- Do you think that rote memorization is truly an essential element of many courses and disciplines?
- Do you think there are circumstances under which putative “essential elements” of core undergraduate courses might actually be excluding students with specific disabilities who otherwise have the skills and talent to succeed?
- Do you think disability support services could or should be doing more to rethink and reframe what is or isn’t “essential”?

### Suggestions & Recommendations

#### 1. Addressing Use of Informal Accommodations & Barriers to Pursuing Formal

**Accommodations.** In surveys and research projects, students often report using informal rather than formal (disability support services-vetted) accommodations.<sup>1</sup> Disability services staff might try to understand the reasons why this happens and develop resources and strategies to address common concerns voiced by students. These concerns include:

- a. Not knowing far enough in advance what to request;
- b. Feeling like generic suggested accommodations would not actually help;
- c. Worrying about the stigma and prejudice associated with invisible disabilities, and concerns that instructors will jump to conclusions based on certain types of formal requests (even in the absence of any direct disclosure);
- d. Needing to get documentation from clinicians or providers who do not know the student well enough or long enough to understand the impact of psychosis on the student or to know what potential accommodations to endorse.

**2. Increased Flexibility.** Campus disability centers could allow (and ideally encourage) students to pursue (or alter) accommodations at any point during a given academic term. Rather than requesting medical documentation specific to each accommodation request, university staff could request more general verification of challenges and broad accommodation strategies, leaving the details (and future variations) to be worked out by the student, disability center staff, and possibly faculty, over the student’s campus career.

**3. In-Depth Exploration of Symptoms and Impact.** Rather than relying on generic accommodations, consider a much more individualized and in-depth exploration of the student's symptoms and challenges, situations and events (such as final exams or oral presentations) that may trigger or exacerbate these symptoms, and a “play-by-play” of how they might impact the student in different types of classes and across different assignments. Be creative in brainstorming modifications, alternatives and strategies that will truly “accommodate” the students' unique challenges and help them live up to their full potential.

**4. Address Primary Symptoms but also Secondary Symptoms and Symptom Triggers.** For many students, symptoms that are secondary to (primary) psychotic symptoms, or symptoms (and events) that trigger primary psychotic symptoms, may either be easier to address or in fact may be more directly responsible for negative impacts. See Figures 1 and 2 below for illustrations.



Figure 1.

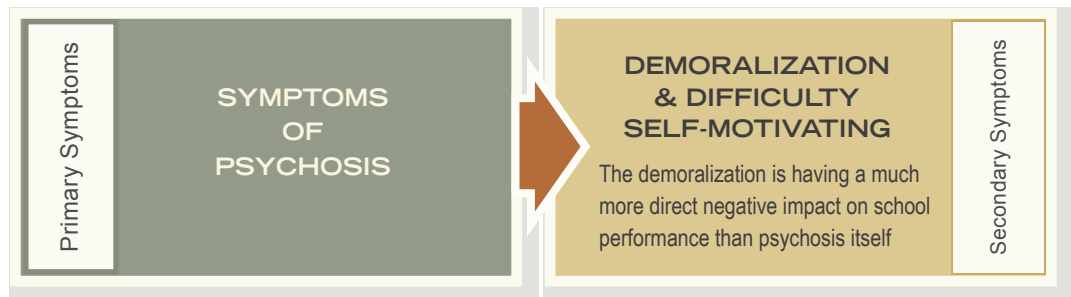


Figure 2.

**5. Understand the Role of Social Stigma & Prejudice.** Empirically, stigma and prejudice associated with psychosis (particularly schizophrenia) are the worst of any major psychiatric disorder.<sup>2</sup> Widespread assumptions that individuals with psychosis are violent and that psychosis is a major cause of campus shootings further reinforce and invigorate existing stereotypes. The impact of stigma on students is often very substantial and may lead to fears and anxiety with respect to direct or indirect disclosure, increased actual risk for students with psychosis (e.g., being reported to a campus threat assessment team), and a more global sense of exclusion and marginalization. Students with psychosis who hear other students or instructors

repeating or endorsing common stereotypes, even if not directed at them, may respond with anger, defensiveness or passive withdrawal. Such feelings can easily lead to difficulties working with others and also directly trigger primary psychotic symptoms (e.g., paranoia or persecutory beliefs and fears). Consider discussing these issues very explicitly with students and factoring them into accommodations, including any accommodations that may be necessary in disciplinary hearings or processes.

- 6. And Internalized Stigma.** Similarly, the impact of internalized stigma on students with psychosis can be substantial, and equally implicated in triggering or exacerbating other symptoms. For instance, a student who feels intense internalized shame about her symptoms and diagnosis may not request accommodations and may push herself to muster through difficult patches on sheer willpower alone. Such decisions may land her in high stress situations (for instance during midterms or finals) in which her symptoms finally flare out of control, without additional supports or any formal accommodations in place. Effective advocacy for and with students who legitimately feel marginalized, judged or ‘at risk’ must consider these types of impacts and the way they can play out in decisions to forego or delay seeking formal accommodations.

## ACCOMMODATION SUGGESTIONS

Accommodations are never “one size fits all” and therefore this brief does not recommend any specific modifications for psychosis. Instead, we suggest thinking as creatively as possible, after exploration of the full (and varied) impact of psychosis on the individual student. Nevertheless, the Toolkit does include two lists of possible accommodations, administrative and course-related (including many which are not included in more generic accommodation lists). Remember that while the impacts of psychosis are significant and can create complicated challenges for students, with the right supports and creative thinking, many more students can and will enter and graduate from college.

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Stein, K. F. DSS and accommodations in higher education: Perceptions of students with psychological disabilities. *Journal of Postsecondary Education and Disability*, 26(2), 146-161.

2 Pescosolido, B. A., Martin, J. K., Long, J. S., Medina, T. R., Phelan, J. C., & Link, B. G. (2010). “A disease like any other”? A decade of change in public reactions to schizophrenia, depression, and alcohol dependence. *The American Journal of Psychiatry*, 167(11), 1321-1330.

# 5

## Administrative Accommodations for Students with Psychosis

Area	Accommodation	Why it might be helpful
<b>Registration and Financial Aid</b>	Counting a part-time course load as full time for financial aid and administrative purposes	A part-time course load can be easier to handle, but the student needs full-time enrollment status for financial aid or other purposes
	Early registration for courses	Helps ensure that student has access to courses most likely to be conducive to his/her success
	Changing a course to a Pass/Fail (rather than graded option) after the switching deadline has passed	A student may experience significant unexpected challenges after the deadline to change course status has passed and want to change to P/NP to avoid negatively impacting his/her GPA
	Allowing student to withdraw from a single class instead of the entire semester, in cases in which full withdrawal would otherwise be the policy	Students with psychosis may have significant disability-related difficulties in just a single class, and waiving full withdrawal policies can allow them to finish as much coursework as possible
	Course refund after the refund deadline has passed	Symptoms force the student to withdraw from a course after the refund deadline but student cannot afford to continue school without a refund
<b>Academic Advising</b>	Permission to request a specific advisor, faculty mentor or project supervisor in cases where other students cannot	Choice will allow the student to work with someone who understands his/her unique disability-related challenges/needs and will not judge him or her for them
	Permission to request a particular placement (e.g., for an internship) in cases where other students cannot	Choice will allow student to intern at a site that he/she knows will be a good fit given disability-related needs and challenges
	Permission to require information and communications in a particular format—for instance, written communications from advisors or departmental staff	Student may have difficulty tracking oral communications or oral communications may create significant anxiety, exacerbate voices, feelings of paranoia or other symptoms
	Permission for a friend, family member or other ally to accompany the student to meetings in which such an individual would not typically be allowed; for instance, a performance review	Having an ally in the room might help diminish social anxiety, feelings of paranoia or other symptoms

(Continued: Administrative Accommodations for Students with Psychosis)

Area	Accommodation	Why it might be helpful
<b>Internships &amp; Practica</b>	Early registration for or preferential placement in internship or practicum of choice	Helps ensure that student has access to the internship site most likely to be conducive to his or her success
	Modified internship or practicum that does not alter essential elements but addresses obstacles students would otherwise face completing it	Examples of modifications include increased flexibility in terms of scheduling and alternate formats (e.g., written instead of oral final presentation) in order to work around students' symptoms and challenges
	Additional mentoring and/or supervision assistance beyond what would normally be provided	Due to disability-related challenges, students may need extra guidance to help them navigate these challenges; for example, navigating symptoms or disclosure as a clinical intern
<b>Residential Services</b>	Preferential placement in residential program/dormitory of choice	Particular symptoms or disability-related challenges (including paranoia, anxiety and phobias) might be addressed or diminished through greater choice over where to live, including a specific building or floor of a building
	Preferential access to private dorm room (no roommate)	Disability-related challenges, such as the need to get very regular hours of sleep, may make it difficult to live with a roommate
<b>Disciplinary Processes</b>	Consideration of disability as a mitigating factor in disciplinary processes (e.g., student conduct code violations)	Challenges or symptoms caused by psychosis are often implicated in alleged misconduct or campus violations and can be considered mitigating factors
	Inclusion of an ally or advocate in disciplinary meetings who otherwise might not be allowed to participate	Having an ally in the room may help diminish social anxiety, feelings of paranoia or other symptoms
	Building specific accommodations into a disciplinary corrections plan	Specific accommodations may prevent a particular behavior from happening; for instance, addressing or reducing triggers that make it harder for the student to control his/her reactions or behaviors when stressed or dealing with disruptive voices or paranoia
	Communications about disciplinary hearings, actions or follow-up must be provided in writing	It may be difficult for the student to track oral communications or they may trigger symptoms; for example, having to communicate in person with someone who has charged the student with misconduct may trigger or significantly exacerbate voices (auditory hallucinations) or paranoia

# 6

## Course-Related Academic Accommodations for Students with Psychosis

Area	Accommodation	Why it might be helpful
<b>Lectures</b>	Assistance with note-taking	It may be difficult to hear or process what instructors are saying & help with taking notes may make it easier to succeed in the course and track assignments
	Copy of instructor's personal notes	An instructor's personal course notes may be more detailed and helpful than the notes another student takes
	Audio-recording lectures	It may be easier to follow lectures at a different time or place, or refer back to them for missed information
	Ability to freely come and go, stand up, sit in an optimal place (preferential seating) or engage in other activities in order to stay alert	Staying active and/or taking breaks may help with concentration, attention and/or fatigue
	Excused absences and flexibility regarding lectures missed due to psychiatric appointments and/or periods of heightened symptoms	Fluctuations in symptoms & associated challenges, as well as the need to attend regular psychiatric appointments, may make it critical that the student has greater flexibility in terms of attendance
	Excused absences granted without the need for excessive documentation (e.g., formal doctor's note)	Students with psychosis may experience unpredictable, periodic exacerbations of symptoms; under such circumstances it may be excessively burdensome to have to justify related absences to instructors or obtain formal medical notes. A waiver of standard documentation can help send the message to instructors that sudden or unpredictable absences are for legitimate disability-related reasons
<b>Class Discussion</b>	Waiver or substitution of comments in a different format for otherwise mandatory class discussion/participation requirements	Voices and feelings of paranoia and anxiety can make it extremely difficult to participate in course discussions in the ways a student otherwise might. Under such circumstances, alternative ways of demonstrating engagement with course material may be extremely helpful

*(Continued: Course-Related Academic Accommodations for Students with Psychosis)*

Area	Accommodation	Why it might be helpful
<b>Group Projects</b>	Substituting an individual project for a group project	Voices, feelings of paranoia and other symptoms can also render participation in a group project very difficult; some students may find it far easier to manage an individual project and such alterations are unlikely to alter the essential requirements of the course
<b>Paired Activities</b>	Intentionally pairing the student with another student with strong skills in situations in which pairing is otherwise random (e.g., randomly selected lab partners in a chemistry class)	In many cases students are randomly paired with a partner in course or lab assignments; in some cases this might mean that the student ends up with a partner with significant academic challenges or weaknesses; it is almost always feasible for instructors, knowing students with disabilities often face multiple additional challenges, to selectively place them with a capable partner
<b>Presentations &amp; Papers</b>	Substituting one format for another: e.g., written presentation/paper in place of an oral presentation	Format substitutions are often among the trickiest accommodations to navigate. Where feasible, however, they can help tremendously with specific psychosis-related challenges. For example, a written paper might be substituted for an oral presentation (which might trigger significant social anxiety, paranoia or voices) or an extended written paper might be substituted for a memory-based exam, allowing the student to demonstrate content mastery in a way that does not hinge on the ability to memorize (or retrieve) factual information
	Flexible extensions ('as needed')	The ability to request extensions on an as-needed-basis without additional medical documentation can be very helpful for students with unpredictable and/or fluctuating symptom levels and associated needs
<b>Exams</b>	Extended testing time	Extending testing time can help address challenges related to attention and memory and also reduce stress and triggers related to time-pressure
	Rescheduling exams during midterms or finals so that they are more evenly spaced (e.g., only one exam per day)	Test-related stress or anxiety can significantly exacerbate symptoms and spacing exams may help reduce these triggers and associated symptoms



*(Continued: Course-Related Academic Accommodations for Students with Psychosis)*

Area	Accommodation	Why it might be helpful
<b>Exams</b>	Ability to use notes during a closed-book exam (or a formula sheet)	In some cases rote memorization may be essential to a course, but in many other cases a test of memory is not needed in order to demonstrate content mastery and such a requirement disproportionately affects high-achieving students who nevertheless have legitimate disabilities involving memory and recall
	Alternative exam format so that course mastery can be demonstrated without exam	A particular exam format (e.g., multiple choice questions, closed book essays) may not in fact be essential to demonstrating course or content mastery, and an alternative format or assignment (such as a term paper) may better accommodate memory and attention challenges as well as other symptoms of psychosis
	Option to re-take or re-do an exam even when this option is not available to other students	Sometimes symptoms may kick in unpredictably after a student has started an exam; under such circumstances it may be legitimate to request a re-take as a formal accommodation
<b>Feedback &amp; Communication</b>	Regular written feedback from instructor, even when not provided to other students	Regular, written feedback can make it easier for students with psychosis to stay on track and better understand relative strengths and weaknesses as a course progresses
	Provision of more detailed or systematic feedback than would otherwise be provided by instructors or teaching assistants	In some cases, instructors may provide only very limited feedback on papers or exams; having additional, detailed feedback can be especially helpful for students already navigating multiple additional psychosis-related challenges and barriers
	Understanding between student and instructor concerning certain triggers and the potential need to suddenly leave class or withdraw from a particular activity on short notice; triggers might be personal, interpersonal, or involve exposure to particular content during lectures or course activities	Many students with psychosis report challenges related to triggering content (such as class discussion of a recent school shooting in which psychosis was believed to play a role) or events ('suspicious' looking electricians fixing a broken heating vent in a classroom); formal accommodations allowing flexibility with respect to breaks, attendance and participation can help communicate to instructors that some reactions or behaviors (suddenly leaving in the middle of a class or presentation) should be understood as disability self-management rather than irresponsibility, disrespect, or violations of course policy



# 7

## Early Psychosis & Violence on Campus: Just the Facts

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Over the past decade, news outlets and policy makers have repeatedly linked campus shootings and campus violence more broadly, to serious mental illness, especially psychosis. But are these links myth or fact?

### Psychosis & Violence

- **Researchers have found that only 0.6% (less than 1/100) of first episode psychosis patients commit violent crimes** leading to serious or permanent injury to the victim.<sup>1</sup> These rates are likely to be much lower among college students with first episode psychosis.
- In contrast, a national longitudinal study found that **11.3 % of emerging adults** (the overwhelming majority of whom reported no serious mental illness) reported involvement in an armed robbery, gang fighting, using a weapon in a fight, pulling a knife or gun on someone, or shooting or stabbing someone in the previous year.<sup>2</sup>
- Another study addressing violent crime in the community found that **only 2.3% of violent crimes could be attributed to individuals with schizophrenia**; rates of violent crime were even *lower* for both women and young adults with schizophrenia or serious mental illness.<sup>3</sup>
- **Less than 5% of 120,000 gun-related killings reported in the U.S. between 2001 and 2010 were perpetrated by people diagnosed with mental illness.**<sup>4</sup>



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“It’s not an exaggeration to say that the conclusions that my teachers and classmates jumped to as soon as I was diagnosed with psychosis, hurt me more than anything else. I felt so sad and lonely and scared, and then instead of supporting me, my advisor suspended me and justified it by claiming that I was likely to do something violent. The message I’d want to send to campus faculty, staff and students is as follows: please, please understand that young people with psychosis need your empathy and support, not fear and rejection.”

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#### RISKS OF VIOLENCE TO OTHERS DWARFED BY RISKS OF VICTIMIZATION

- Individuals with serious mental illness are far more likely to be the victims of violence than the perpetrators. A 2008 review of available studies found that **only 2-13% of consumers in outpatient settings had committed violent offenses but 20-34% had been violently victimized.**<sup>5</sup>

#### OTHER RISK FACTORS FOR CAMPUS VIOLENCE

- Substance abuse and past history of misconduct are both significantly higher predictors of violent crime than serious mental illness; 41% of violent crimes against college students were perpetrated by an offender perceived to be using drugs, including 40% of all rape/sexual assaults and approximately 25% of all robberies.<sup>6</sup>

### How Stigma Impacts Emerging Adults with Early Psychosis

- **An estimated 40% of young adults with first episode psychosis report thoughts of suicide, and 31% attempt suicide; among this same group, 53% report experiencing significant stigma/prejudice and 50% social exclusion.**<sup>7</sup>
- The internalization of social stigma is strongly linked to suicide risk and poor outcomes among individuals with psychosis;<sup>8</sup> **college students with mental illness consistently describe stigma as one of the most significant barriers to their success and well-being on campus.**<sup>9</sup>

## Additional Readings

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Jones, N., Brown, R., Keys, C. B., & Salzer, M. (2015). Beyond symptoms? Investigating predictors of sense of campus belonging among postsecondary students with psychiatric disabilities. *Journal of Community Psychology*, 43(5), 594-610.

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Salzer, M. S., Wick, L. C., & Rogers, J. A. (2008). Familiarity with and use of accommodations and supports among postsecondary students with mental illnesses. *Psychiatric Services*, 59(4), 370-375.

<sup>1</sup> Large, M. M., & Nielssen, O. (2011). Violence in first-episode psychosis: a systematic review and meta-analysis. *Schizophrenia Research*, 125(2), 209-220.

<sup>2</sup> Marcus, R. F. (2009). *Cross-sectional study of violence in emerging adulthood*. *Aggressive Behavior*, 35(2), 188-202.

<sup>3</sup> Psych, M. R. C., Grann, M., & Psych, C. (2006). The population impact of severe mental illness on violent crime. *American Journal of Psychiatry*, 163(8), 1397-1403.

<sup>4</sup> Metz, J. M., & MacLeish, K. T. (2015). Mental illness, mass shootings, and the politics of American firearms. *American Journal of Public Health*, 105(2), 240-249.

<sup>5</sup> Choe, J. Y., Teplin, L. A., & Abram, K. M. (2008). Perpetration of violence, violent victimization, and severe mental illness: Balancing public health concerns. *Psychiatric Services*, 59(2), 153-164.

<sup>6</sup> Hart, T. C. (2003). *Violent victimization of college students*. Bureau of Justice Statistics (BJS), US Department of Justice, Office of Justice Programs.

<sup>7</sup> Tarrier, N., Khan, S., Cater, J., & Picken, A. (2007). The subjective consequences of suffering a first episode psychosis: trauma and suicide behaviour. *Social Psychiatry and Psychiatric Epidemiology*, 42(1), 29-35.

<sup>8</sup> Yanos, P. T., Roe, D., Markus, K., & Lysaker, P. H. (2008). Pathways between internalized stigma and outcomes related to recovery in schizophrenia spectrum disorders. *Psychiatric Services*, 59(12), 1437-1442.

<sup>9</sup> Collins, M. E., & Mowbray, C. T. (2008). Students with psychiatric disabilities on campus: Examining predictors of enrollment with disability support services. *Journal of Postsecondary Education and Disability*, 21(2), 91-104.

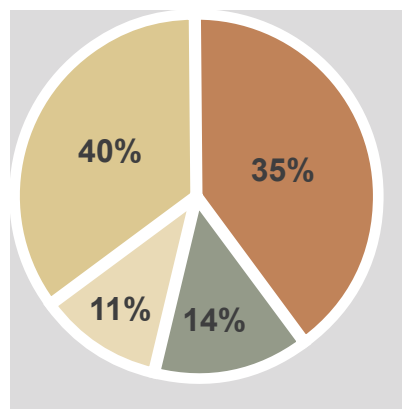
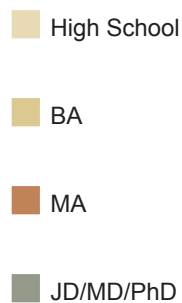
<sup>10</sup> Wynaden, D., McAllister, M., Tohotoa, J., Al Omari, O., Heslop, K., Duggan, R., ... & Byrne, L. (2014). The silence of mental health issues within university environments: A quantitative study. *Archives of Psychiatric Nursing*, 28(5), 339-344.

## 8

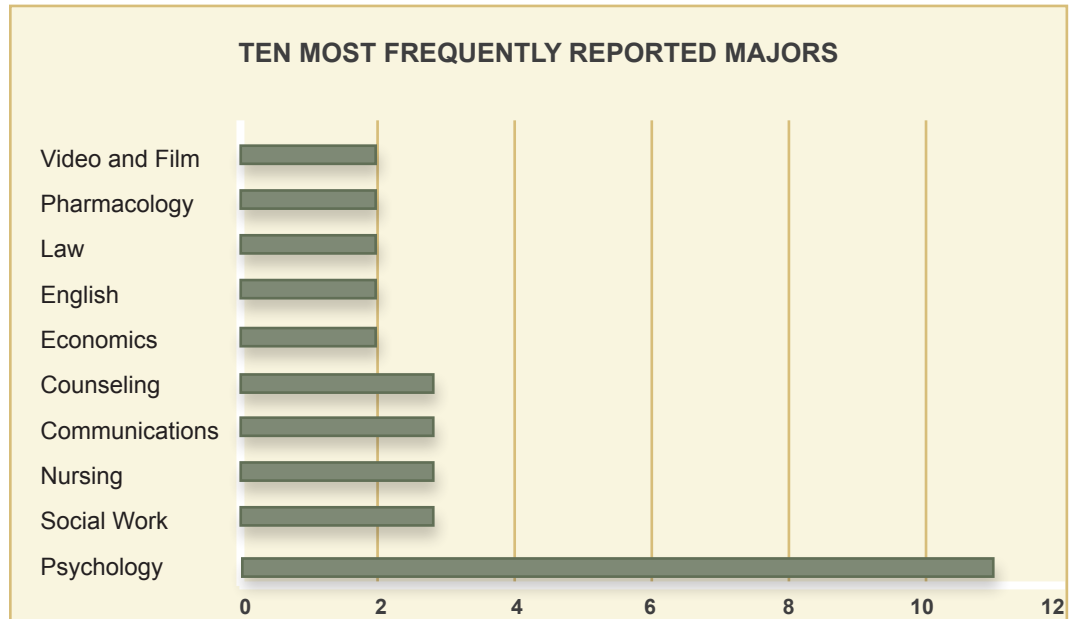
## Voices of Success: The Work & School Stories Project

Unfortunately, successful adults with a history and diagnosis of psychosis are largely invisible in society due primarily to stigma and the risks of speaking out. This invisibility can send young people (and their family and academic mentors) the message that success across an array of fields and disciplines is unlikely. The [Work & School Stories Project](http://www.voicesoutside.org) ([www.voicesoutside.org](http://www.voicesoutside.org)) is a non-proprietary advocacy initiative aimed at increasing the visibility of “success stories.” To date, 80 people have completed the project survey, including current undergraduate, graduate and doctoral students and university graduates with a variety of degrees. Careers reported by participants include high level non-profit and corporate executives, business associates, clinical psychologists and social workers, lawyers/law students, researchers, engineers and computer programmers, multiple writers and artists, two documentary film-makers, a high school principal and a pediatrician.

### HIGHEST DEGREES



The majority of participants, particularly those working in non-mental health fields, reported opting not to disclose to colleagues at work or school, or disclosing only very selectively to mentors or close friends. Many reported making use of informal accommodations in place of, or in addition to, formal accommodations while in school and stressed the importance of having supervisors or mentors with an understanding of the participant's challenges along with strong investment in supporting them.



All participants were asked if they had any advice for young people who had recently experienced a first break. A few of the responses:

- “There ARE people out there who care and who can help. Seek them out. You also have the ability within you to help yourself if you seek it. Learn from your experiences. It may not seem like it at times, but they will make you more insightful about yourself and others and more motivated about your work, whatever it ends up being.”
- “If you can find a way to see your experience with psychosis as an opportunity rather than a curse, you have taken the first and most significant step towards finding your purpose. Ask yourself what unique gifts/passion/wisdom/perspective your experiences have provided to you, and how you can help others with that.”
- “Go forth and be your awesome self, there are going to be times when it is tough, no matter what your career choice, but surround yourself with people who believe in you and always remember one simple truth, the fire that forged you is the same fire that drives you to keep going and to make a difference to yourself and others. Don’t give up and choose wisely when you give in, and be proud always of your own story.”

## FURTHER REFLECTIONS ON SCHOOL AND SUCCESS:

"I came to law school with a passion for social justice and human rights. My goal is to incorporate my personal passions with my work, in the hopes of affecting real change and providing access to justice for those who are often ignored or harmed by the legal system.

Recently, I have worked with aboriginal clients in an underprivileged community, providing pro bono representation and legal advice. I also work with a local legal organization on a volunteer basis, which provides work on campaigns addressing human rights and systemic issues, such as poverty. I also sit on the diversity board within the law school, and work with other students to provide the greater student body with education and information on a variety of diversity initiatives, such as LGBTQ rights, mental health issues, privilege and power workshops, aboriginal issues, etc. The study of law and work that I do can be extremely challenging and stressful. The environment is not particularly conducive to mental health, even in students who were previously mentally "healthy". However, the work can also be very rewarding, and provides me with the opportunity to serve my community."



"The 'ironic' nature of my research (i.e., someone diagnosed with psychosis actually doing research in the very same area) means I am very very motivated to prove that I can and will complete my PhD and contribute to the wider scientific community. I want to change the misconception that psychosis completely ruins one's life and any future aspirations. Every day is a productive day and it makes me feel a great sense of fulfilment! Recent accomplishments would include completing a large behavioral study with over 100 participants on subclinical/nonclinical psychotic experiences and investigating their relationships with certain cognitive mechanisms."

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## Suggested Memoirs & Other Readings

Frese, F. J., Knight, E. L., & Saks, E. (2009). Recovery from schizophrenia: With views of psychiatrists, psychologists, and others diagnosed with this disorder. *Schizophrenia Bulletin*, 35(2), 370-380.

Hawkes, E. L. (2012). *When quietness came: A neuroscientist's personal journey with schizophrenia*. Bridgeross Communications.

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McFarling, U. (2016). A journey through schizophrenia, from researcher to patient and back. STAT. Accessed at <https://www.statnews.com/2016/06/14/schizophrenia-journey/>

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# 9

## Responding Compassionately to Students Experiencing Psychosis in the Context of Withdrawals and Leaves of Absence: An Information Brief for Campus Staff

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Over the past few decades, the number of students with significant psychiatric disabilities in postsecondary settings has been steadily rising. Faculty and other members of the campus community are increasingly likely to interact with students with either recent onset or established psychosis. Unfortunately, few members of the campus community receive training in engaging and working with students with more significant mental health challenges, at times leading to fear, miscommunication and unwarranted suspensions and/or involuntary leaves of absence. In several recent cases, campus responses to a mental health crisis have been implicated in students subsequently taking their own lives.

### THE STUDENT'S EXPERIENCE OF PSYCHOSIS

Psychosis refers to a group of related symptoms (including hearing voices and paranoia) often described as involving a “break” with reality. Psychotic symptoms can appear suddenly and very acutely, or “creep up” very slowly. Some young people are painfully aware of how their world is changing, while others are unable to recognize that aspects of their experience are no longer “really real.” The onset of psychosis is often terrifying and disorienting and can lead to significant social isolation, depression and pronounced risk of suicide. In spite of common stereotypes, young people with early psychosis are in fact at substantially greater risk of hurting themselves than harming others. Please see the [Early Psychosis and Violence: Just the Facts information brief](#) for additional information. In some cases, psychosis can also lead students to do or say things that they otherwise never would. For instance, a student experiencing overwhelming delusions might steal small objects from a campus office, thinking that the tokens she takes are essential to securing world peace, or she may angrily accuse a faculty member of colluding with the FBI (or the Islamic State).



## ENCOUNTERING STUDENTS WITH PSYCHOSIS

Acute psychotic symptoms are often alarming not only to the person experiencing them, but also to those interacting with them. Most campus staff members have no training in psychosis. Encountering active psychotic symptoms can be confusing and disorienting. Without additional context as to the student's history, symptoms and/or diagnosis, a faculty or staff member might instead assume that the student's behaviors stem from intentional misconduct, misbehavior or delinquency. Primed by misleading stereotypes about psychosis, staff may also jump to the conclusion that the student is potentially violent and/or a threat to campus safety.



“Other students and faculty were terrified of me—the minute they found out. I almost couldn't believe that people who I thought I knew well and who knew me so well could suddenly treat me not just like a stranger but like a criminal. More than anything, I just wanted a hug, someone to hold my hand through all of it, but instead it seemed like whoever I was—this nice, warm and fuzzy person—had disappeared and all they could see was a very scary person, a potential threat. I've never felt so alone. I cannot over-emphasize how important it is to make sure that people feel supported rather than rejected.”

## POTENTIALLY HARMFUL RESPONSES TO STUDENTS EXPERIENCING PSYCHOSIS

The negative impacts of endorsed stereotypes on empathy are empirically well-established. Once a student is placed in the “box” of potential risk or threat rather than a struggling young person in need of support, empathy can erode. Too often campus staff respond with hostility and fear. Examples of potentially harmful campus responses to psychosis and significant mental illness include:

- Faculty/instructors refusing to return emails, meet or engage with a student experiencing active symptoms, often without explanation;
- Faculty or Administrators immediately referring students to campus security and/or a threat assessment team without adequate cause;
- Taking disciplinary actions and responding to putative disciplinary violations and imposing sanctions in ways that fail to consider a student's disability as a mitigating factor;
- Responding in a way that is motivated by potential legal liability rather than a commitment to helping and supporting the student;

- Using unnecessarily impersonal and ‘matter of fact’ communications (such as formal letters of dismissal or suspension);
- Direct or indirect communications suggesting that the student might be better off taking a leave of absence or not returning to school after a voluntary or involuntary leave of absence.

***Remember that a student who is on a leave of absence is still your student and they need supports to remain in school and succeed.***

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“The first time I went to the campus disability office I was scared and really hesitant and the first thing the director said was “I hope you realize that you don’t have a right to any accommodations; this isn’t high school.”

That was how the whole conversation went....that tone of voice. When I got back to my room, I cried and cried. Later on, one of my professors told me that he didn’t think someone with schizophrenia could ever succeed. I

didn’t say anything then but after that became angry and—according to professors—hostile at times in class. I couldn’t help it—I felt so judged and misunderstood and angry. I cried a lot at night. And then I eventually got told that my conduct was a problem... that I wasn’t acting “professionally” in classes. That I needed to learn to control my emotions better. And the pain I felt was almost too much for me. Things were so hard anyway, and then there was all of this judgment on top of it.”

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### **Withdrawal, Suspension & Discipline: the Impact on Students**

Entering, attending and graduating from college can serve as profoundly important milestones for students and lay the foundation for bigger life goals and dreams. Unexpected poor performance in school and other disruptions due to significant mental health issues such as withdrawals or leaves of absence can be devastating in and of themselves (and put the student at significant risk for suicide). Loss of structure and purpose stemming from a leave of absence or withdrawal from classes can also aggravate or exacerbate symptoms of psychosis or precipitate a more serious relapse. In many cases, remaining in school with additional supports is in the best interest of the student. When psychiatric challenges are so severe that a leave of absence is necessary, it is still critically important for campus staff and administration to do what they can to ensure that the student feels supported, remains connected to the campus, and will be welcomed back to campus. Experiences of rejection and/or marginalization by faculty, staff and/or other students following a psychotic break or episode can also devastate students’ confidence and morale.

## COMPASSIONATE RESPONDING: MEETINGS & COMMUNICATIONS

Responding with empathy and compassion need not take any more time or resources than responding in a neutral or punitive way. Specific recommendations follow.

### Faculty-Student Communications

DO	DON'T
<p>Express your concern and empathy for the student, even if you feel unable to directly help or don't understand what the student is saying. For example "it seems like you're really struggling/having a hard time. I'm concerned about you and don't feel like I'm in a position to help but want to make sure you're connected with any supports you need."</p>	<p><b>Ignore or avoid the student</b>, or send a cold or unfriendly email such as "<i>I am unavailable for meetings at this time;</i>" or "<i>Please contact a mental health professional.</i>" Don't ignore statements of distress and only respond to concerns regarding grades and performance.</p>
<p><b>Communicate the expectation that, even if an interruption seems likely, the student will remain in or return to school.</b> For example, express willingness to work through incompletes in the future ("<i>don't worry about this now, when you get back we'll meet and figure out a plan for addressing the incomplete</i>"), or general re-assurance ("<i>look forward to working with you in the future</i>").</p>	<p><b>Assume or imply that the student is unlikely to return to campus.</b> For example "<i>so sorry things didn't work out here.</i>"</p>
<p><b>Convey your firm belief in the student's potential and ability to pursue their goals</b> and that their experiences/diagnosis have not negatively impacted your support for them. For example "<i>I just want you to know that I have total faith in your ability to succeed;</i>" or "<i>I want to assure you that your diagnosis/experiences/challenges do not affect the way I view you as a student and I would be happy to write a strong letter of recommendation in the future.</i>"</p>	<p><b>Suggest that the student should reconsider a major, program of study or related career goals.</b> For example "<i>you might want to think some more about a high stress field like mechanical engineering;</i>" or "<i>maybe you'd want to take some time off and then revisit continuing in this program.</i>" Don't suggest that the student isn't a good fit for the program or major.</p>

## Administrative Communications

DO	DON'T
<p><b>Express empathy for the student</b>, even in otherwise perfunctory legal communications. For example, in a letter regarding a leave of absence consider adding language such as:</p> <ul style="list-style-type: none"> <li>• “We realize that taking time off can be difficult and we hope you’ll stay in touch with mentors and friends while you’re off.”</li> <li>• “We consider you a valued member of the campus community and look forward to your return.</li> <li>• “We’re here to help. Please don’t hesitate to contact us with any questions or concerns.”</li> </ul>	<p><b>Limit communications to cold or excessively legalistic language.</b> For example: “the university/program regrets to inform you that you will be placed on involuntary leave effective XYZ. Please collect your belongings by ABC. You are banned from campus and if found on campus will be arrested for trespassing.”</p>
<p><b>Communicate the expectation that, even if an interruption is likely or certain, the student will return to school.</b> For example, if you need any assistance when you return to campus, contact XYZ.”</p>	<p><b>Assume or imply that the student is unlikely to return to campus.</b> For example, “Please be aware that you would need to re-apply for admission following leave and there is no guarantee that you will be accepted.”</p>
<p><b>If possible, assign the student a campus advocate or liaison</b> that is available to answer questions, assist with the transition back to campus, and help navigate paperwork, including conditional reinstatement appeals.</p>	<p><b>Describe difficult or unclear procedures or protocol (such as a complicated conditional reinstatement appeal processes) without</b> offering additional support, information and/or guidance.</p>

## SUPPORTING STUDENTS DURING INVOLUNTARY LEAVE

Concerned primarily with risk and potential legal liability, many schools ban students who have been placed on involuntary leave from campus housing and prohibit them from visiting friends in campus housing. Such decisions can be extremely damaging to individuals whose identity as students (and campus-based relationships and group involvements) can be central to their sense of self and well-being. In spite of clear evidence as to the importance of sustained structured activity (including work and school) for recovery from a first break or serious psychiatric disability, beliefs that “taking a break” and/or returning to a family home far from campus are the best thing for students persist. Suggestions for supporting students in circumstances under which leave is unavoidable include:

- Allowing students to maintain connections, friendships and extracurricular involvements on campus;
- Assigning a mentor, coordinator or campus liaison who can help to keep the student stay connected and ease their transition back to school;
- Developing a positive, strengths-based “welcome back packet” for students returning to school after involuntary leave.

## Summary

Acute psychosis is often confusing and disorienting, both for the student experiencing it, and faculty, staff and classmates who interact with the student. Pervasive negative stereotypes about psychosis may make it that much harder to respond with empathy and compassion rather than fear. However, in many cases, even simple expressions of empathy, concern and faith in the student's ability to stay at or return to classes and campus life can go a long way toward reassuring and supporting the student.

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<sup>1</sup> Siegel, R. & Wang, V. (2015). Student death raises questions on withdrawal policies. Yale Daily News. Accessed at <http://yaledailynews.com/blog/2015/01/29/student-death-raises-questions-on-withdrawal-policies/>

Kingkade, T. (2014). Using college mental health services can lead to students getting removed from campus. Huffington Post. Accessed at [http://www.huffingtonpost.com/2014/10/07/college-mental-health-services\\_n\\_5900632.html](http://www.huffingtonpost.com/2014/10/07/college-mental-health-services_n_5900632.html)

<sup>2</sup> Nordentoft, M., Jeppesen, P., Abel, M., Kasso, P., Petersen, L., Thorup, A., ... & Jørgensen, P. (2002). OPUS study: suicidal behaviour, suicidal ideation and hopelessness among patients with first-episode psychosis. *The British Journal of Psychiatry*, 181(43), s98-s106.

Tarrier, N., Khan, S., Cater, J., & Picken, A. (2007). The subjective consequences of suffering a first episode psychosis: trauma and suicide behaviour. *Social Psychiatry and Psychiatric Epidemiology*, 42(1), 29-35.

<sup>3</sup> Batson, C. D., & Ahmad, N. Y. (2009). Using empathy to improve intergroup attitudes and relations. *Social Issues and Policy Review*, 3(1), 141-177.

Cikara, M., Bruneau, E. G., & Saxe, R. R. (2011). Us and them intergroup failures of empathy. *Current Directions in Psychological Science*, 20(3), 149-153.

# 10

## Increasing Early Psychosis Awareness and Supports & Challenging Stigma on Campus: Guidance for Campus Leaders

### THE PROBLEM

The public media and some policy makers have readily linked school shootings and campus violence with serious mental illness, particularly psychosis. Unfortunately, recent campus-based awareness, anti-stigma, suicide reduction and student wellness initiatives have tended to shy away from advocating for the specific needs and concerns of students with psychosis/schizophrenia and challenging the damaging stereotypes associated with these experiences.

### OPPORTUNITY

With the implementation of the national mental health block grant set-aside and the broad expansion of specialized early intervention in psychosis programs around the country, the opportunity to leverage the momentum of student anti-stigma, suicide prevention and wellness initiatives on college campuses is high.

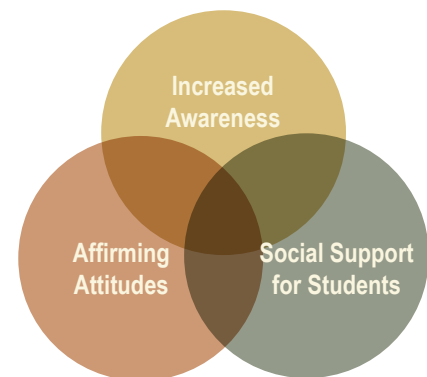


Figure 1. Components of Campus Change

## A FRAMEWORK FOR CHANGE

Simultaneously increasing awareness and promoting early detection while providing tangible supports for students is always a balancing act. Focusing too strongly on early detection can inadvertently send the message that once someone has helped a student “get help,” their work is done. To thrive, however, students who have recently experienced a first episode of psychosis don’t just need clinical treatment, but ongoing encouragement and support. A holistic framework of campus change, as depicted in Figure 1, emphasizes a three-pronged approach which includes:

1. Increasing awareness of early signs and indicators of psychosis;
2. Promoting affirming attitudes about the potential of students with psychosis, in addition to reducing negative stigma and stereotypes;
3. Building the capacity of faculty, staff and students to provide ongoing social support and encouragement to students struggling with psychosis and other serious psychiatric disabilities.

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## INCREASING AWARENESS

**Recommendation 1:** *On at least an annual basis sponsor trainings targeting key campus constituencies to increase awareness of the early signs and symptoms of early psychosis.*

### How to Do This:

1. **Make use of mandatory orientations** (for new faculty, new staff, new residence assistants and new students) to set-aside dedicated training time focused on early psychosis and psychiatric disabilities.
2. Ensure that **all campus counseling and health center staff**, as well as members of campus threat assessment teams, receive additional training in early recognition and detection.
3. **Regularly sponsor ‘one touch’ awareness events**, such as a speaking panel during mental health awareness month, and make sure that psychosis (ideally a speaker with personal experience of psychosis) is explicitly included.
4. **Link with any local early intervention in psychosis programs**, which may be able to provide trainings at no cost.
5. Encourage departments and relevant campus centers to consider **inviting speakers or organizing events on the general topic of psychosis** or serious mental illness.

**Recommendation 2:** Hire or train an in-house staff expert or ‘champion’ with in-depth understanding of serious psychiatric disabilities.

**How to Do This:**

1. Hire or identify an in-house staff member with in-depth understanding of psychosis and the ability to train other staff, who can also serve as a consultant or point person when issues or challenges arise involving a student with psychosis or other serious psychiatric disability.
2. If no existing staff member has this expertise, and hiring a new staff member is not possible, invest in training someone to fill this role. For instance, cover tuition and costs for relevant coursework, support them to attend key conferences on psychosis and serious mental illness and to participate in webinars and other low-cost training opportunities.

**Recommendation 3:** Make high quality “increasing awareness” or “early detection” materials available on institutional websites and as printed flyers available in key student support offices.

**How to Do This:**

1. Post (online) and print copies of the Early Detection & Early Engagement guidance sheet included in the Back to School Toolkit (or similar materials from another project).
2. Ensure that any institutional or department websites that deal with mental health explicitly include psychosis; available mental health or disability-related materials should not be limited to depression, anxiety, and eating disorders.

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## PROMOTING AFFIRMING ATTITUDES (AND REDUCING STIGMA)

Leading stigma reduction experts have underscored the importance of not merely reducing negative attitudes toward persons with psychiatric disabilities, but also promoting affirming attitudes—i.e., beliefs that even those with the most serious psychiatric diagnoses can thrive and lead satisfying professional and social lives.<sup>1</sup> In a campus setting, perhaps more than anywhere else, this means effectively communicating the message that students with histories of psychosis can (and do) succeed even with the most ambitious academic and career goals.

**Recommendation 1:** Support evidence-based on-campus stigma reduction programs and events that, wherever possible, feature current/former students with personal experience of psychosis.

**How to Do This:**

1. Work with local specialty early intervention in psychosis services, youth mental health programs, and/or mental health advocacy organizations to provide at least annual or semi-annual awareness and stigma reduction panels or events.
2. Ensure that any events or workshops follow established best practices for reducing stigma and increasing affirming attitudes: see Table 1 (below) for more detailed suggestions based on Corrigan’s evidence-based TLC3 stigma reduction model.



Table 1 Corrigan's TLC3 (Targeted Local Credible Continuous Contact) Model of Stigma Change

Principle	Explanation	Example of Application in Campus Psychosis Stigma Reduction Program
<b>Contact is fundamental to change public stigma</b>	<ul style="list-style-type: none"> <li>Exposure to and interaction with real people who have the diagnosis or experiences in question is a critical component of changing attitudes</li> <li>High quality stigma reduction programs will include individuals with personal experience</li> </ul>	Panel of current/former students with mental health challenges, including at least one with personal experience of psychosis, presents and interacts with the audience, putting a human face on psychosis
<b>Programs need to be targeted</b>	<ul style="list-style-type: none"> <li>Programs should be carefully targeted for a specific audience (for example students, or athletes, or STEM majors)</li> <li>Messaging should be tailored to the target group</li> </ul>	Panels or presentations are explicitly targeted to different campus groups, such as: (1) faculty & instructors; (2) residential assistants; (3) undergraduates; (4) staff involved in the institution's threat assessment process; (5) clinical/counseling staff at the institution
<b>Local programs are more effective</b>	<ul style="list-style-type: none"> <li>Programs should focus on the specific needs of individuals in a particular geographical area or setting</li> <li>Content should be tailored to the demographics of the setting</li> </ul>	Content should be carefully tailored to the particular institution. The stereotypes that would need to be tackled among graduate faculty at an elite research institution, for instance, could be very different from those of instructors at a college that predominantly serves under-represented, first generation students
<b>Presenters must be credible</b>	<ul style="list-style-type: none"> <li>Presenters must be perceived as credible to participants in terms of their experience and who they are</li> <li>For example, a successful college graduate with depression would be unlikely to be viewed as a representative of the challenges/successes of a student with psychosis or schizophrenia</li> </ul>	For psychosis stigma reduction, at least one presenter must have had "credible" experiences of psychosis, including a significant enough treatment and symptom history. For example, a student who experienced voices for a short period in the aftermath of a traumatic event, and never struggled with symptoms while on campus, would likely be seen as less credible than a current student with ongoing symptoms and challenges.
<b>Engagement must be continuous/ongoing</b>	<ul style="list-style-type: none"> <li>A single stigma reduction event is unlikely to lead to lasting change, unless additional events and opportunities that reinforce the same messages are offered regularly and repeatedly</li> <li>Programs should "penetrate" a given setting in terms of both time and diverse target audiences</li> </ul>	Programs that target different campus audiences are offered on a regular basis, and efforts are made to include all new faculty and staff, including graduate instructors/teaching fellows

**Recommendation 2:** Ensure that ‘affirmative’ disability sensitivity and competency trainings, explicitly including highly stigmatized diagnoses such as psychosis and other serious psychiatric disabilities, are provided to all new faculty, teaching assistants and staff in relevant positions.

#### How to Do This:



- 1. Identify faculty and staff** in positions that are likely to involve interaction with students with psychiatric disabilities (for instance disability services staff, campus counseling staff, residential assistants, Dean’s offices, and all teaching faculty and assistants).
- Mandate that new faculty/new staff orientations (as relevant) include **disability sensitivity and competency trainings with material that focuses (explicitly) on psychosis and other serious psychiatric disabilities.**
- Ensure that these trainings promote “affirming attitudes”** and increase understanding both of the challenges that students with psychosis and other serious psychiatric disabilities face and their potential to succeed and flourish (academically and vocationally) with adequate supports.

**Recommendation 3:** Perform an annual or biennial ‘campus diversity climate’ survey or needs assessment adapted to include at least some items focused explicitly on psychosis and/or significant psychiatric disabilities/serious mental illness.

#### How to Do This:

- 1. Select an appropriate assessment tool.** Possibilities include the Assessment of Campus Climate to Enhance Student Success (ACCESS) survey, the Campus Climate and Disabilities Questionnaires (CCDQ), and Baker’s Campus Perceptions of Persons with Disabilities Survey.<sup>3</sup>
- Consider including both standard disability climate items and **items specifically geared toward assessing attitudes related to known areas of stigma, such as strength of perceived links between campus shootings and schizophrenia.** See examples of adapted or additional items in Table 2.
- Ideally, finalize a survey tool through a participatory process involving diverse campus stakeholders, such as disability center staff, faculty or instructors, and students with experience of psychiatric disabilities, including psychosis.

Table 2. Measuring Familiarity &amp; Attitudes Toward Students with Psychosis

Adaptation of Existing Tool* **
I am sensitive to the needs of students with schizophrenia and other serious mental illnesses.
I know what the term “psychosis” means.
I am familiar with section 504 of the Rehabilitation Act of 1973 and the Americans with Disabilities Act (1990), and the specific implications for students with serious mental illness in institutions of higher education.
Students with schizophrenia and other serious mental illnesses are able to compete academically at the college level.
I think of students differently after they approach me about a need for accommodations and disclose a serious mental illness.
Additional (Novel) Psychosis-Specific Items
I believe that untreated serious mental illnesses such as schizophrenia have played a significant role in campus shootings over the past 15 years.
I think that faculty and campus staff should have greater discretion with respect to reporting or communicating with parents about students they suspect of untreated mental illness such as psychosis.
My institution has not gone far enough to address the risk that students with untreated mental illness can pose to the campus community.

\* 5-point Likert scale from strongly disagree to strongly agree; \*\* Adapted from Baker et al. (2012)

**Recommendation 4:** Report results from a climate survey or needs assessment back to the campus community and use these results to inform a strategic plan and concrete responses.

#### How to Do This:

1. Hire or identify an in-house staff member with in-depth understanding of psychosis and the ability **to train other staff, who can also serve as a consultant or point person when issues or challenges arise involving a student with psychosis** or other serious psychiatric disability.
2. If no existing staff member has this expertise, and hiring a new staff member is not possible, **invest in training someone to fill this role**; for instance, cover tuition and costs for relevant coursework, support them to attend key conferences on psychosis and serious mental illness and to participate in webinars and other low-cost training opportunities.

## BUILDING SOCIAL SUPPORT FOR STUDENTS

**Recommendation 1:** Wherever possible, balance or supplement awareness and early detection-oriented trainings and events with activities that promote and encourage direct social support for (and the full community inclusion of) students with psychosis.

### How to Do This:

- 1. Sponsor or support messaging that encourages empathy or support for students with psychosis,** rather than the narrower ability to detect psychosis and refer students to treatment. For example, Active Minds' Unity Campaign asks that members of the campus community provide not just referrals but a “safe space for persons to discuss mental health” challenges (see sidebar).
- 2. Sponsor or support student peer-to-peer support models,** that help build the skills and capacity of students in the areas of active listening and interpersonal support. Longstanding models of campus peer-to-peer programs include Yale's Walden Peer Counseling model<sup>5</sup> and Student-to-Student Peer Counseling at the University of California at Berkeley.<sup>6</sup> As with other programs, it is important to make sure that student peer counselors have at least some training in early psychosis and that policies do not prevent them from working with students with psychosis or other significant psychiatric disabilities/serious mental illness.

#### Active Minds' Unity Campaign Pledge

- End the silence by providing a safe space for persons to discuss mental health
- Listen to mental health experiences without judgment
- Be knowledgeable of available resources
- Treat every person as a capable and valuable individual in our community
- Speak out against stigma and discrimination towards people with mental illness

## Conclusion

All too often, campus-based awareness, stigma reduction and student support programs exclude, de-emphasize or under-represent realities, experiences, challenges, and needs associated with psychosis and other psychiatric disabilities perceived as ‘severe’ or ‘serious.’ Within the mental health spectrum, stereotypes and prejudice about psychosis are particularly strong and intransigent,<sup>7</sup> and educational gaps are substantially worse for individuals with psychotic diagnoses compared to many other disability groups. The recommendations included in this guidance module were developed to support the implementation of best practices in these areas and the full inclusion of the needs and challenges of students with psychosis.

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<sup>1</sup> Corrigan, P. W., Powell, K. J., & Michaels, P. J. (2014). Brief battery for measurement of stigmatizing versus affirming attitudes about mental illness. *Psychiatry Research*, 215(2), 466-470.

Corrigan, P. W., & Shapiro, J. R. (2010). Measuring the impact of programs that challenge the public stigma of mental illness. *Clinical Psychology Review*, 30(8), 907-922.

<sup>2</sup> Corrigan, P. W. (2011). Strategic Stigma Change (SSC): Five principles for social marketing campaigns to reduce stigma. *Psychiatric Services*, 62(8), 824-826.

Corrigan, P.W., Michaels, P. & Buchholz, B. (n.d.) Strategic stigma change: *Principles for social marketing campaigns meant to erase the prejudice and discrimination of mental illness*. Accessed online at [http://www.stigmaandempowerment.org/images/stories/TLC\\_3\\_summary\\_doc\\_Final\\_for\\_NCSE\\_webpage.pdf](http://www.stigmaandempowerment.org/images/stories/TLC_3_summary_doc_Final_for_NCSE_webpage.pdf)

<sup>3</sup> Baker, K. Q., Boland, K., & Nowik, C. M. (2012). A campus survey of faculty and student perceptions of persons with disabilities. *Journal of Postsecondary Education and Disability*, 25(4), 309-329.

Vogel, S. A. (2011). Campus Climate and Disabilities Questionnaires™: *Faculty, administrators and staff, students without disabilities, and students with disabilities*. Lincolnshire, IL: Campus Climate and Disabilities, LLC.

Vogel, S. A., Holt, J. K., Sligar, S., & Leake, E. (2008). Assessment of campus climate to enhance student success. *Journal of Postsecondary Education and Disability*, 21(1), 15-31.

<sup>4</sup> Baker, K. Q., Boland, K., & Nowik, C. M. (2012). A campus survey of faculty and student perceptions of persons with disabilities. *Journal of Postsecondary Education and Disability*, 25(4), 309-329.

<sup>5</sup> Walden Peer Counseling. (n.d.). Yale University. <http://walden.sites.yale.edu/about-us>

<sup>6</sup> Student to Student Peer Counseling. (n.d.). University of California at Berkeley. <http://sspc.berkeley.edu/about/>

<sup>7</sup> Pescosolido, B. A., Martin, J. K., Long, J. S., Medina, T. R., Phelan, J. C., & Link, B. G. (2010). “A disease like any other”? A decade of change in public reactions to schizophrenia, depression, and alcohol dependence. *The American Journal of Psychiatry*, 167(11), 1321-1330.

## Increasing Access and Addressing Achievement Gaps among Students with Psychosis: Guidance for Campus Leaders

### THE PROBLEM

Educational disparities for individuals with serious psychiatric disabilities are higher than almost all other disabilities groups. Long-term unemployment for individuals with a schizophrenia diagnosis ranges from 60 to 80%,<sup>1</sup> and underemployment rates are likely even higher. Nevertheless, the majority of individuals with serious psychiatric disabilities (including psychosis) indicate a desire to return to school.<sup>2</sup>

### OPPORTUNITY

With the implementation of the national mental health block grant set-aside and the associated increase in the number of specialized early intervention in psychosis programs around the country, the number of emerging adults with psychosis who aspire to attend college is like to increase significantly. This expansion of clinical supports creates both a need for collaboration and campus-based program development along with a significant opportunity to help close significant achievement gaps.

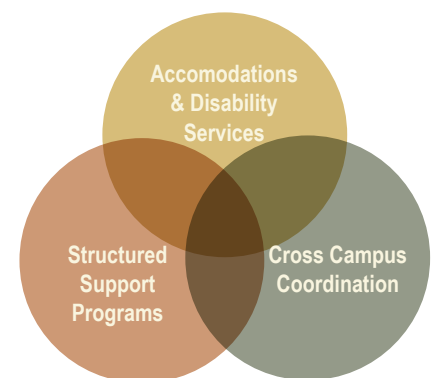


Figure 1. Addressing Achievement Gaps

## A FRAMEWORK FOR CHANGE

Traditionally, supports for students with psychiatric disabilities have revolved around accommodations provided by a campus disability services office and mental health counseling centers. Given the magnitude of the social, societal and symptom-driven challenges associated with psychosis and other serious psychiatric disabilities, however, accommodations and clinical supports alone are insufficient to bridge persistent access and achievement gaps. This guidance module focuses on change in three key areas:

1. **Improving accommodations & disability services** to better meet the specific needs of students with psychosis and other significant psychiatric disabilities;
2. **Structured academic and professional support programs**, including mentoring and summer enrichment or bridge programs;
3. **The coordination of services and supports across campus divisions and administrative units**, in order to ensure that students' needs are met efficiently and holistically.

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## ACCOMMODATIONS & DISABILITY SUPPORT SERVICES

As mentioned above, ample research supports the claim that students with significant psychiatric disabilities often face unique barriers and obstacles accessing, successfully using, and maximizing the benefits of accommodations and disability support services. A common concern is that disability accommodations and services do not adequately target or serve the unique needs and challenges of students with complicated mental health challenges to eliminate barriers, and disability services offices are often not staffed by disability counselors with an in-depth understanding of the symptoms, impacts, social stigma and societal reactions experienced by students with psychosis. Students also report faculty who are at times hostile to students with psychiatric disabilities.<sup>3</sup> In order to address such gaps, consider stronger efforts to explicitly identify and remove barriers faced by students with psychosis and other significant psychiatric disabilities, and develop initiatives to increase the skills, capacity and understanding of staff and faculty.

**Recommendation 1:** Provide targeted guidance on the array of accommodations likely to address the specific needs of students with psychosis.

### How to Do This:

1. **Make psychosis-specific accommodations lists and guidance available both online and in print** through the disability services office. The disability support staff information sheet, accommodations lists, and student/family accommodations guidance included in this Toolkit can all be used or adapted.
2. **Encourage disability support staff to provide targeted guidance, responsive to student's specific individual challenges and diagnosis**, rather than generic guidance (and lists of suggested accommodations).

**Recommendation 2:** Hire or train at least one disability services staff member with specific expertise working with students with psychiatric disabilities, including psychosis.

**How to Do This:**

1. Hire or identify an in-house disability services staff member with in-depth understanding of psychosis and the ability **to train other staff, who can also serve as a consultant or point person when issues or challenges arise involving a student with psychosis** or other serious psychiatric disability.

**Recommendation 3:** Provide targeted trainings for all disability services staff on effectively accommodating students with psychosis and other significant psychiatric disabilities.

**How to Do This:**

1. Use an in-house staff with expertise in serious psychiatric disabilities and/or hire external trainers or consultants to **build the background knowledge, skills, and understanding of all disability services staff**. At a minimum, ensure that staff understand the symptoms of psychosis and their impact on students, are trained to use non-stigmatizing language in interacting with students, and are able to think creatively about the sorts of accommodations that might be necessary to accommodate complex and unpredictable psychiatric symptoms.
2. **Consider working with a local specialty early intervention in psychosis program** to develop or deliver trainings on psychosis, its impact, and support strategies.

**Recommendation 4:** Provide faculty and staff with education about students with psychiatric disabilities including psychosis, and provide targeted trainings and resources that contextualize the challenges which students with psychosis and other significant disabilities face, and challenge stereotypes about student use of academic accommodations.

**How to Do This:**

1. **Require that all new faculty and instructors (including graduate students and teaching assistants) participate in trainings** or didactics that effectively challenge common faculty stereotypes about student use of accommodations, and increase knowledge and understanding of psychosis as well as other significant psychiatric disabilities and their impact on students.
2. **Consider contracting or partnering with local specialty early intervention in psychosis services** to develop or provide such trainings.
3. **Support department chairs in addressing attitudinal and training barriers and obstacles** within their own departments and among their staff.



## STRUCTURED SUPPORT PROGRAMS

Educational disparities, including lower than average attendance, retention and graduation rates, are not unique to psychosis (or significant psychiatric disability): many groups, for one reason or other, are under-represented in higher education and face multiple additional barriers and obstacles to postsecondary success. This means that a wide range of strategies and interventions have already been developed to help under-represented or at-risk students including: mentoring, bridge programs, enrichment programs and various fellowship and leadership development models.<sup>4</sup> Recommendations in this section come primarily from existing approaches developed for first-generation, ethnic/racial and economically disadvantaged students.

**Recommendation 1:** Provide structured support programs that explicitly include students with significant psychiatric disabilities or that treat such students as a priority population.

### How to Do This:

- 1. Use or consider applying for federal TRIO Student Support Services Program (TRIO SSS) funds.** The TRIO SSS program is explicitly designed to help support low income first generation college students as well as students with disabilities facing academic challenges. If TRIO funds are unavailable, consider similar programs funded in a different way.
- 2. Provide SSS participants additional supports and resources**, including: targeted assistance with academic plans, career development and financial aid assistance; individual tutoring and/or supplemental workshops and trainings to strengthen academic skills; and mentoring and guidance from staff, senior students or alumni. Include explicit guidance on navigating disclosure with a highly-stigmatized diagnosis. Work with trained disability services staff to maximize tailored supports.
- 3. Ensure that program staff are trained to work with, and understand the unique challenges of, students with psychosis** and other significant psychiatric disabilities.
- 4. Effectively communicate eligibility for services to the student body** and make sure that faculty and staff in disability services and campus counseling are aware of available services, and actively refer eligible students.

**Recommendation 2:** Develop dedicated mentoring programs for students with significant psychiatric disabilities that match students with mentors who either have personal experience or a strong understanding of psychiatric disabilities and commitment to supporting students.

### How to Do This:

- 1. Identify existing mentoring programs or initiatives** (including alumni mentoring programs) that could be expanded or adapted to better serve students with significant psychiatric disabilities.

2. **Explore peer-to-peer mentoring program possibilities**, including student clubs and organizations which may already operate some type of campus “buddy” program or help support such a program.

**Recommendation 3:** Provide dedicated academic enrichment and/or fellowship programs, or explicitly target students with psychosis and other significant psychiatric disabilities for broader enrichment programs aimed at increasing the number of students who complete particular degree programs and/or pursue advanced degrees.

#### How to Do This:



1. Identify existing programs (whether summer enrichment programs, TRIO funded programs such as the **federal McNair Postbaccalaureate Achievement Program**, or similar models) and **determine the feasibility of explicitly recruiting and including students with significant psychiatric disabilities**.
2. **Explicitly address key challenges** facing students with significant psychiatric disabilities in fields and disciplines requiring licensure (including law, medicine and clinical psychology) including the impact of symptoms, stigma and prejudice, and the implications of disclosure and/or treatment history.
3. **Ensure that program staff are trained to work with, and understand the unique challenges of, students with psychosis** and other significant psychiatric disabilities.

4. **Effectively communicate eligibility for enrichment and fellowship programs to the student body** and make sure that faculty and staff in disability services and campus counseling are aware of eligibility and actively refer eligible students.

**Recommendation 4:** Operate non-academic leadership development programs such as increasing student involvement in extracurricular activities, civic engagement, and other areas.

#### How to Do This:

1. Most postsecondary institutions already operate a wide variety of leadership development programs that augment a student’s academic coursework with programs, workshops and activities or stipend-based projects. **Explore the feasibility of including students with significant psychiatric disabilities more fully or explicitly in such programs**.
2. **Consider developing programs more narrowly developed to support and strengthen leadership among students with significant psychiatric disabilities**. For example, a program focusing on mental health policy and advocacy or direct community mental health volunteerism for students with personal experience.

## CAMPUSWIDE SERVICE COORDINATION

Many postsecondary institutions are structured in ways that result in a lack of continuity/connection between that various staff members, divisions and departments with which student with psychosis (or other complicated disabilities) are likely to interact. Many campus services are also premised on a model that requires student self-advocacy, but there are serious risks and downsides to such models when it comes to students newly navigating institutional systems following a first episode of psychosis, much less in the midst of a psychotic episode. The expectation that students experiencing significant paranoia, hostile voices, severe social anxiety and/or altered states can effectively navigate complex services is not only unrealistic but it also contributes to needs going unaddressed or under-addressed for excessively long periods of time, potentially putting the student (or others) at risk.

**Recommendation 1:** Employ dedicated social worker(s) or service coordinators who serve the dedicated function of coordinating campus services and supports for students with complex psychiatric needs and challenges.

### How to Do This:

1. If dedicated service coordination staff do not already exist, develop a scope of work and position description that includes:
  - a. Working to meet the needs of students with complex disabilities;
  - b. Coordinating services offered by different institutional departments;
  - c. Linking the student (and other staff) with external resources;
  - d. Liaising with parents or family as necessary and/or requested;
  - e. Participating in campus emergency planning and threat assessment activities;
  - f. Serving as an advocate for the student.
2. Ensure that campus staff and faculty are aware of service coordinator roles and able to refer students who might benefit from such services.

**Recommendation 2:** Encourage and incentivize staff from relevant departments (Dean of Students Office, disability support services, campus counseling) to regularly meet and discuss campus issues of shared concern related to significant psychiatric disabilities. Be sure that supporting students with psychiatric disabilities is a central focus of such meetings and coordination, rather than risk mitigation or threat assessment.

**How to Do This:**

- 1. Develop an interdepartmental coordinating committee for psychiatric disabilities** or similar group with representation from all divisions and departments with a clear stake in policy and services for students with psychiatric disabilities.
- 2. At a minimum, ensure that staff from different divisions (e.g., campus counseling and disability services) meet, talk and exchange respective expertise as it related to mental health policies and supports.**



**Recommendation 3:** Ensure that staff from all relevant departments are involved in campus emergency/threat assessment planning, and, as appropriate, that faculty and staff

are made aware of actions taken vis-à-vis students with whom they are working without violating privacy protections afforded by FERPA and/or HIPAA. For instance, if a student is suddenly hospitalized and cannot directly contact faculty, instructors of courses they are enrolled in, or supervisors for campus jobs, should be informed that the student cannot attend class or work due to a medical emergency. Failing to do so may jeopardize the student's grades, ability to complete the course, relationships with faculty/supervisors and/or job.

**How to Do This:**

- 1. Develop clear notification protocols and a notification point person who will assume responsibility for alerting faculty and supervisors** to absences due to a medical emergency.
- 2. Make sure that faculty and/or supervisors do not take unnecessary actions in the instance of a sudden, prolonged or otherwise unexplained absence** (such as hiring a replacement or dropping the student from a course or project).

## Summary

With adequate supports and encouragement, student with early psychosis and other significant psychiatric disabilities stand to make significant contributions to society, and they should enjoy the same broad 'rights' as members of other under-represented groups to education and societal inclusion and integration. In order to ensure robust inclusion and representation, however, postsecondary institutions must invest in providing such students with the targeted supports they need, challenging entrenched prejudice and marginalization, and encouraging and sustaining leadership in academics as well campus social and civic activities.



<sup>1</sup> Morgan, C., Lappin, J., Heslin, M., Donoghue, K., Lomas, B., Reininghaus, U., ... & Fearon, P. (2014). Reappraising the long-term course and outcome of psychotic disorders: The AESOP-10 study. *Psychological Medicine*, 44(13), 2713-2726.

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<sup>2</sup> Corrigan, P. W., Barr, L., Driscoll, H., & Boyle, M. G. (2007). The educational goals of people with psychiatric disabilities. *Psychiatric Rehabilitation Journal*, 32(1), 67-70.

<sup>3</sup> Becker, M., Martin, L., Wajeeh, E., Ward, J., & Shern, D. (2001). Students with mental illnesses in a university setting: faculty and student attitudes, beliefs, knowledge, and experiences. *Psychiatric Rehabilitation Journal*, 25(4), 359-368.

Brockelman, K. F., Chadsey, J. G., & Loeb, J. W. (2005). Faculty perceptions of university students with psychiatric disabilities. *Psychiatric Rehabilitation Journal*, 30(1), 23-30.

<sup>4</sup> Ishiyama, J. T., & Hopkins, V. M. (2003). Assessing the impact of a graduate school preparation program on first-generation, low-income college students at a public liberal arts university. *Journal of College Student Retention: Research, Theory & Practice*, 4(4), 393-405.

James, D. W., Jurich, S., & Estes, S. (2001). *Raising minority academic achievement: A compendium of education programs and practices*. American Youth Policy Forum. Accessed at <http://www.aypf.org/wp-content/uploads/2014/07/book.pdf>

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## Resources

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### LEGAL ADVOCACY GROUPS

[Bazelon Center for Mental Health Law](#). Includes information on campus mental health policy, legislation, and current legal cases.

[National Disability Rights Network](#). Includes a comprehensive directory of state-level protection & advocacy (P&A) networks and programs around the US. P&As typically provide free legal consultation for students who believe they have experienced disability-related discrimination.

### ACADEMIC ACCOMMODATIONS

[Webinar - Tools for School: College Accommodations for Students with Psychiatric Disabilities](#). University of Massachusetts Transitions Research & Training Center.

[Getting Accommodations at College: Tools for School](#). University of Massachusetts Transitions Research & Training Center.

[Academic Adjustments](#). Boston University Center for Psychiatric Rehabilitation.

[How Does Mental Illness Affect My School Performance?](#) Boston University Center for Psychiatric Rehabilitation.

### CAMPUS POLICY, STUDENTS RIGHTS & OTHER GUIDES

[Campus Mental Health: Know Your Rights!](#) Bazelon Center for Mental Health Law and Leadership 21.

[Supporting Students: A Model Policy for Colleges and Universities](#). Bazelon Center and Temple Collaborative on Community Inclusion of People with Psychiatric Disabilities

[Beyond Compliance: An Information Packet on the Inclusion of People with Disabilities in Postsecondary Education.](#) Syracuse University Beyond Compliance Coordinating Committee.

[A Practical Guide for Students with Disabilities Who Want to Go to College.](#) Temple University Collaborative On Community Inclusion of People with Psychiatric Disabilities.

[Rights of Students with Disabilities in Higher Education.](#) Disability Rights California.

[Making My Way Through College: A Guide for Students with Disabilities.](#) National Collaborative on Workforce and Disability.

[Going to College: A Virtual Resource For Teens with Disabilities.](#) Virginia Commonwealth University.

## **SUPPORTED EDUCATION**

[Supported Education Toolkit.](#) University of Kansas Center for Mental Health Research & Innovation.

[Developing Supported Education Programs at California Universities: A Toolkit of Possibilities.](#) California Social Work Education Council.

## **CAMPUS MENTAL HEALTH ADVOCACY & STIGMA REDUCTION**

[Jed Foundation](#)

[Active Minds](#)

[NAMI on Campus](#)

[Honest Open Proud on College Campuses](#)

[Young People in Recovery](#) (addictions; young adult rather than campus focused)

[Youth M.O.V.E National](#) (youth & young adult rather than campus focused)

## **NATIONAL ORGANIZATIONS & PROFESSIONAL ASSOCIATIONS**

[American College Mental Health Association \(ACMHA\)](#)

[Association of Higher Education and Disability \(AHEAD\)](#)

[Association for University & College Campus Counseling Directors \(AUCCCD\)](#)

[Association of Recovery in Higher Education \(ARHE\)](#). Addictions focused.

## MISCELLANEOUS BLOGS & RESOURCE COMPILATIONS

[Law Office of Karen Bower: Focusing on Campus Mental Health Issues.](#)

[Education Resources.](#) Temple University Collaborative on Community Inclusion of Individuals with Psychiatric Disabilities.

[Work & School Stories Project:](#) compilation of accounts by people with psychosis successful in a variety of disciplines and careers. Part of the Voices Outside Project.

[Centre for Innovation in Campus Mental Health.](#) Canada.

## SCHOLARSHIPS FOR STUDENTS WITH PSYCHIATRIC DISABILITIES

[Baer Reintegration Scholarship.](#) Center for Reintegration.

[Charles A. Olayinka Memorial Scholarship.](#)

[JC Runyon Foundation Scholarships.](#)

## EARLY PSYCHOSIS & EARLY INTERVENTION RESOURCES

[Early Intervention in Psychosis Treatment Program Lists & Links.](#) National Association of State Mental Health Program Directors (NASMHPD).

[Recovery After An Initial Schizophrenia Episode \(RAISE\).](#) National Institute of Mental Health.

[Prodrome and Early Psychosis Program Network \(PEPPNET\).](#) Stanford University.

[Partners for Strong Minds.](#) (Formerly the National Psychosis Prevention Council). A project of the One Mind Institute (IMHRO).

## PEER-TO-PEER YOUNG ADULT EARLY PSYCHOSIS RESOURCES

[Voice Collective \(UK\)](#)

[Is Anyone Else Like Me? The EYE Project: Engaging Young People Early in Mental Health & Wellbeing for Psychosis \(UK\)](#)



## YOUTH- AND PEER-LED DOCUMENTARIES & ANIMATIONS ON PSYCHOSIS

[Simon Says: Psychosis!](#) “A film about the experience of psychosis and the positive role that early intervention services can play in that often rocky voyage. Subjects explored include: What is psychosis? How does it feel to have psychosis? Is psychosis a breakdown or a breakthrough?”

[Psychosis is Nothing Like a Badger.](#) “Psychosis is a serious mental health issue that can affect anyone - yet many still view the illness from a stigmatized, stereotyped, and fearful perspective. It’s also nothing like a badger. This is an animation about how and why psychosis affects people the way it does, in order to raise awareness and, hopefully, reduce the stigma attached to the illness.”

[A Little Insight.](#) “During 2012, 5 young people (aged 12-18) came together to create a short animation from the ground up. The young people wrote, filmed and edited the animation, with the support from Aoife from [Chocolate Films](#). The project reached the shortlist of the Rob Knox 2013 Film Festival.”