



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

This Toolkit is one of a two-part series. The companion Toolkit is geared towards campus staff and administrators.

STUDENT & FAMILY VERSION

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Introduction & Orientation

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 more specific groups (such as campus disability support services staff, administrators, counseling center staff, parents and students), along with other materials that are intended for a cross-stakeholder audience. Two separate Toolkits are available: one targets students and families; and the other is geared toward 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. Certain components that are relevant to both broad groups are replicated in each Toolkit.

The Back to School Toolkits were 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 mental health attorney who specializes in higher education-related issues.



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Introduction & Orientation for Students

INTRODUCTION

Depending on who you are, returning to school after hospitalization(s) or intensive treatment for psychosis might seem: completely overwhelming; difficult but doable; or no big deal. Regardless of your initial feelings, the complex array of campus services, policies, supports and procedures can be confusing and difficult to navigate. Returning to campus with psychosis is also likely to raise multiple new questions and decision points: Will you disclose to faculty? To other students? Are there academic accommodations that would help? Who will you turn to if things go wrong?

“I guess I would just like other students to know that they can do it. That psychosis is really just a new beginning rather than the end of their dreams or hopes for the future.”

— ‘Robyn’



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 address academic accommodations and legal troubleshooting. **This section covers:**

- [Advance planning & communication](#)
- [Establishing relationships with campus staff](#)
- [Supporting your own well-being](#)
- [Campus self-advocacy](#)
- [Navigating disclosure](#)
- [Campus stigma](#)



Advance Planning & Communication

Mental health challenges, almost by definition, create uncertainties about what might happen in the future. Regardless of the treatment you’re engaged in or any medications you’re taking, symptoms associated with psychosis might: be steady; come and go unpredictably; or fade altogether until they’re exacerbated by stressors that are common in college (Think: midterms or finals). Given all the things that could happen, it is important to consider advance planning: thinking through, and ideally writing down, what you’d want to happen and who you’d want involved in case of a crisis or emergency. Advance plans can be developed informally as guidance for friends and family, or more formally as a notarized “psychiatric advance directive,” a legally binding statement of your wishes with respect to future treatment. While local regulations vary, medical advance directives are legally binding across the U.S., and 25 states have adopted policies specific to psychiatric advance directives. Visit the [National Resource Center on Psychiatric Advance Directives](#) for further information.

While there is less precedent for the use of formal psychiatric advance directives (PADs) in campus settings, consider filing a copy with both the Dean of Students office and the campus counseling or campus health center. In an on-campus emergency, staff at the Dean of Students Office and/or campus counseling or health center are likely to be among the first notified if not directly involved. If your goal is to create a more informal plan for friends and family, make sure that they have a copy and that you have walked them through your reasoning and have done whatever you can to make sure that they understand what you want and why.

Writing an advance plan also gives you the opportunity to think through such issues as: when and under what circumstances you might want family members to be notified (or get involved); who would bring you schoolwork if you were suddenly hospitalized; and who would notify your professors or instructors.

Suggested Advance Planning Topics:

- **Family Consent.** Think about who you might want to be able to discuss your situation with university administrative and counseling staff (and/or off-campus clinicians) and under what circumstances. Find out whether or not specific campus consent forms are already available and where you would need to file them. If you are a dependent, you can sign a consent form to enable administrative officials to share information from your education record with designated family members. You might also consider introducing friends or classmates to your family or sharing contact information just in case it becomes necessary for them to connect.
- **External & Campus-Based Clinicians.** If you have (or plan to work with) both external and internal (campus-based) clinicians, what relationship do you want them to have with each other? Think about both the short term and emergency circumstances that might arise in the future. If you want internal and external clinicians to be able to interact in non-emergency circumstances, you'll likely need to provide written consent. Consent forms may need to be renewed every year. Consider this same question for other types of campus staff, such as coordinators working within the Dean of Students Office or elsewhere.
- **Faculty & Academic Advisors or Department Leads.** Similarly, think through what sort of communication you would ideally want to see between either your family and faculty/advisors, or clinicians (external or internal) and faculty/advisors. This may be especially important if you work very closely with a single campus staff member or advisor.
- **Types of Mental Health Treatment.** In a formal psychiatric advance directive, you can specify where (if feasible) you'd like to be treated—for instance a particular hospital, if a bed is available—and what services you'd find most helpful within an inpatient setting, and why that type of medication or treatment works best for you.
- **Staying Near School or Returning Home.** If you're in school in a different state or geographically distant from parents and family, it may be helpful to clarify any circumstances under which you'd be okay going to a hospital or clinic back home versus staying within the same area as your school.
- **Withdrawals or Incompletes.** In some cases—typically only in the instance of an extended, serious emergency—other people or your family might end up needing to make decisions about withdrawals or taking incompletes in courses. Think through what you might want to happen under such circumstances.



Establishing Relationships with Campus Counseling and Administrative Staff

While there are a lot of commonalities across campuses when it comes to mental health-related services and resources, there are also always plenty of campus-specific differences. While you're in the process of preparing to return to school, or first getting settled in, we strongly recommend setting aside time to explore what's available in the way of campus services and supports, as well as policies and procedures related to mental health and disability.

Specific Suggestions:

- **Establish Initial Relationships with Faculty & Staff.** Even if you opt not to access certain services—for example academic accommodations or on-campus counseling—at the beginning, it can't hurt (and might prove invaluable in the future) to get to know key staff in areas like disability services, counseling, or the Dean of Students Office. You might also consider starting to build relationships with administrative staff in your major or program (if you've declared or are in a specific program or track).
- **Make Targeted Disclosure to Faculty or Staff.** While there are undeniably risks associated with disclosing (whether to staff or other students), staff, friends and classmates may be much better equipped to help you in an emergency if they have some idea of your history and challenges. For instance, you might consider letting residential advisors, academic advisors, on campus supervisors and/or support staff within a specific program or department, know about your challenges
- **Establish Relationships with Student Housing Assistants & Staff.** If you live in a dorm or other student housing setting with residential assistant(s) or a residence hall leader, you may also want to consider targeted disclosure and perhaps take more time than you otherwise would to establish friendly relationships.
- **Create Documentation of Disability:** Unlike in high school, college students must follow school procedures and apply for accommodations through a disability services office in order to formally establish disability and receive formal accommodations. Even if you do not use the accommodations, it may be worthwhile to get them approved so that they are available if you need them or in order to ensure formal documentation of disability for other reasons. For example, you must have formally documented disability in order to file an accommodations-related complaint with the Department of Education or Department of Justice. See more in the Toolkit's Navigating Accommodations module.

RETURNING TO SCHOOL AWAY FROM HOME?

For some students, it makes the most sense to attend school in the same city or region as one's family/parents, as well as trusted clinicians or a specialized early psychosis treatment team. Other students, however, aim to return to (or start) school outside of their home area or state. If this describes you, here are some questions you might want to ask:

- ✓ **Your Current Clinicians.** Are your current clinicians willing or able to provide adjunctive supports even once you've left the area? If not, are they willing/able to debrief your new clinician(s) or team? Are they willing to provide Skype or other remote support? Will they continue seeing you during breaks and visits home?
- ✓ **New Services.** What on- or off-campus services are available where you plan to go to school? If you've discovered particular supports or a therapeutic approach that works for you, can you find a new clinician with the same approach or values? If not, do you have alternative strategies for maintaining and sustaining your well-being?
- ✓ **Events in the Past.** If your studies were interrupted by psychosis, and you're now returning to school after a break, do you anticipate any challenges? (For instance, if you feel like you did embarrassing things because of unaddressed symptoms and are not sure how to navigate this.) If so, how will you handle such challenges?
- ✓ **Family Communication.** How often will you communicate with family members? Might it make sense to schedule a regular check-in time so that they know that you're okay?



Supporting Your Personal Well-Being

For nearly everyone, college can be a wonderful experience, but also intensely stressful. The nature of academic coursework is also such that the pressure and stress is not evenly distributed (e.g., compare the first couple of weeks in a semester to mid-terms or finals). In addition to academic stressors, most students are simultaneously facing multiple additional financial, social and romantic challenges, as well as an irregular schedule, late nights studying and disrupted sleep. Substance use (drugs and alcohol) are also typically widespread in campus settings, and pose additional risks and challenges for students already struggling with significant mental health challenges.

“When I think about my experiences in college...so many lessons learned.

At the end of the day, I think you have to work really hard to get to know yourself: what you can handle, what's too much, when you need help, when you need to check in with someone. “

—‘Stephanie’

“It took me a while: one semester I took on too much, then I got really depressed and withdrew... But with support and plenty of my own effort, I feel like I gradually figured out how to make it all work. And that process has been invaluable. I needed the opportunity and space to figure all of this out, and college gave me that.”

—‘Adrian’

So...there is plenty that can go wrong. Although you know yourself better than anyone, consider some general guidelines for campus well-being:

Structure. Structure—i.e., regular activities that you do every day, like attending class, spending a set amount of time studying in a café or library, cooking dinner with friends—is often critical to (any) student’s well-being, but is especially important with the myriad of challenges that can come along with psychosis in the picture. A regular bedtime and healthy eating and sleeping habits are also very important.

Pacing. It’s often easier for students returning to school to take things easy initially, at least until you feel like you have a handle on things. For some people this might mean taking fewer classes (or starting with just one), and for others balancing a full-time load of harder courses with easier ones. Most colleges and universities also offer physical education (e.g., classes in dance or yoga) that can not only counter-balance more difficult academic courses, but directly contribute to both physical and mental well-being.

Support Network. Depending on your situation, you may already have a strong support network on campus or need to build one. *The importance of social supports cannot be overstated.* Family is part of this, but also advisors and mentors, teaching assistants,

clinicians, friends and other students in your courses who can provide help if you miss a class or have a question about an assignment you need answered at 1 AM. Talking and meeting with people on a regular basis can also help you stay grounded and connected. Campus groups such as NAMI or Active Minds can provide support.

Sleeping and Eating. Links between both regular sleep and psychiatric symptoms, and healthy eating and psychiatric symptoms are well-established. Campus life can pose huge challenges in terms of both functions, making it all the more important that you make sure that you're getting enough sleep, and eating well.

Minimizing Drugs & Alcohol. Moderate recreational drug and alcohol use can be a common part of campus social life and, for some people, abstinence may feel like a counterproductive barrier to fitting in. Alcohol and drugs can interact with psychiatric medications, however, in potentially dangerous ways and may also trigger or exacerbate symptoms. Your challenge is to figure out how to set boundaries, minimize harms, and either avoid activities and situations that might trigger a more significant crisis (or exacerbation), or else participate in ways that support your own stability (for instance, going to a bar with friends but drinking non-alcoholic beverages).

Knowing your Personal Triggers & Stressors. Are finals likely to exacerbate your voices so much that you can barely concentrate? Will a required oral presentation push feelings of paranoia over the top? Perhaps nothing is more central to success (and recovery) than an understanding of your personal triggers and the ability to anticipate and plan for (or around) them. Having accommodations (and disability documentation in place) even if you're not actively using them, can also decrease stress and anxiety, especially if you unexpectedly encounter difficulties or worsening symptoms.

Internalized Stigma & Lowered Self-Expectations. It can be extremely difficult, given societal attitudes toward psychosis and media misrepresentation, not to internalize the idea that you're now flawed, less capable than others, and unable or unlikely to succeed in life. These feelings can easily lead to a more general state of demoralization and apathy, or what researchers have described to as the "why try effect:" if you won't succeed at anything anyway, why even try. Some ways of addressing low self-esteem and demoralization include:

- **Doing things that you're good at** and, perhaps most importantly, make you feel confident and competent, even if they are non-academic (for instance, baking amazing cupcakes, or painting or knitting).
- **Fighting back** using your own experiences and challenges, including experiences of prejudice and discrimination, to fuel efforts to change attitudes and systems.
- **Staying busy and focusing on short-to-medium term goals.** The less you worry about things that may or may not happen in the distant future (e.g., graduating but not getting a job, never finding a romantic partner) the harder it will be to motivate yourself in the short term. Small wins or successes will help you build your confidence back up and counter fears that your dreams and goals are now out of reach.

Self-Advocacy on Campus

Unfortunately, most students are likely to engage with (or seek help from) campus faculty or staff at some point who themselves lack understanding of psychiatric disabilities, of available campus or community services, and of relevant policy and/or law. Even if the person you're talking to seems very confident, always do your own research and, if necessary, get a "second opinion" or ask around. In some cases more drastic steps (such as filing a complaint or contacting a legal advocate) may be necessary—see Section 6 of this guide.



“When I initially asked at the disability center, they gave me a list of accommodations, but none of them seemed at all relevant. I suggested a couple of ideas, but the staff member I spoke to immediately ruled them out. It was only several years later, and following a lot of unnecessary difficulties, that I finally realized the range of accommodations one can legitimately request so long as the right rationale and documentation are in place.... Sometimes you’ve just got to fight to get your needs met, even though in an ideal world it would be a lot easier.”

—‘Luke’

Whenever you can, also consider speaking up or communicating your challenges (and ideas) to administrators. While it might seem like a solitary letter or email won't make a difference, over time, messages and communications do add up. And, if administrators are not aware of specific problems or challenges, they can't address them.

Collective advocacy through student groups or organizations can also be a powerful way to influence services, raise awareness and call attention to challenges and barriers. Many campuses have mental health or disability-related student groups, including chapters of well-established national organizations like NAMI and Active Minds.

Navigating Disclosure

Figuring out who to disclose to, when, and under what circumstances, is always a highly individual process. Some general considerations are nevertheless worth exploring. In addition, for students interested in a more structured approach to disclosure decision-making, consider exploring resources available through the [Honest Open Proud program \(HOPp\) for college students](#). Although it designed as a multi-week peer led decision-making program, the HOPp website includes both the manual and workbook used in campus HOPp programs and provides multiple tools designed to help students weigh the pros and cons of disclosure.

Disability Services Staff. The ADA requires students to self-identify to disability services staff and provide some documentation of disability in order to receive formal accommodations. While some students opt to avoid formal documentations, it's important to note that foregoing the formal accommodations process (including documentation) may lead to difficulties later on if the student encounters discrimination, experiences an acute episode or suddenly finds him/herself in need of an administrative accommodation or modification. For example, if a student starts hearing distressing voices the day of an exam, and fails the exam without having any documentation in place (or accommodations), it may be difficult or impossible to argue that the poor performance was due to psychosis/voices and that retrospective accommodations should be made.

Faculty and Advisors. In the authors' experience, students often struggle the most with decisions as to whether to disclose to faculty/instructors or an academic advisor. On the one hand, the stigma is real, on the other, it can be incredibly difficult to navigate rough patches without an internal ally within your program or department. Many graduate and professional students we've spoken with have gone so far as to recommend choosing an advisor on the basis of their willingness to work with and around psychiatric disabilities and transferring advisors if they're not. Even if you're already set on disclosing, consider thinking carefully about how much detail to go into and what details to cover or leave out.

Faculty disclosure decisions may be more complicated for students in programs requiring licensure, certification or clinical practica (for instance nursing, counseling or social work), particularly when significant psychiatric disabilities might be perceived as a potential barrier to licensure or professional practice. Because of the additional risks and implications of disclosure in such programs, consider taking as much time as you can to "feel things out" and ask around before approaching faculty or staff with your story.

“I cannot imagine having been successful in my program without my advisor’s understanding and support. He consistently advocated for me, negotiated with the department for greater flexibility and was someone I didn’t hesitate to turn to for advice. As far as I’m concerned, my symptoms were always way too unpredictable to handle through the university’s bureaucratic accommodations system. His understanding of all that I was going through, and his willingness to work with me on the fly, was what allowed me not just to get through, but to thrive.

— ‘Javier’

Other Students. Many students with psychosis report significant benefits (reduced anxiety, increased acceptance and inclusion) from selective disclosure to close friends. Deciding whether or not to disclose more publicly (e.g., to an entire class, or all the members of an academic cohort) carries more potential risks. Also keep in mind that other students are not under any legal obligation with respect to confidentiality or privacy, and so once you have come out to a large number of people, this information is likely to spread well beyond that initial group.

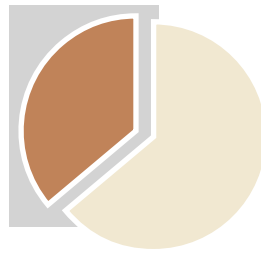
Campus Stigma

Unfortunately, campus stigma is real, and can extend not just to students and staff but also faculty and administrators. In a national survey of 382 college students with psychiatric disabilities, for example, 56% reported feeling embarrassed about disclosing to faculty in order to access accommodations, 56% reported fears of being stigmatized by faculty, and 42% reported that faculty were uncooperative or unreceptive to accommodation requests (Salzer et al., 2008).



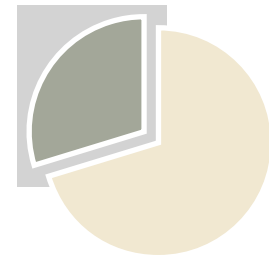
56%

Reported feeling embarrassed about disclosing to faculty in order to access accommodations,



56%

Reported fears of being stigmatized by faculty



42%

Reported that faculty were uncooperative or unreceptive to accommodation requests

Drawing on a different national survey of graduate psychology program admissions chairs, another group of researchers concluded that disclosure of a mental illness during the applications process was a “kiss of death” (Appleby & Appleby, 2006).

All told, stigma on college campuses is unfortunately very real. On the one hand, this means that *you are not alone*. The vast majority of students with psychosis experience or are exposed to negative attitudes and/or behavioral discrimination. Sharing these experiences with others and discussing strategies for dealing with them can be deeply healing. In settings in which such sharing is not possible, however, ongoing exposure to stigmatizing attitudes from other students, staff and/or faculty can feel overwhelming.

Fortunately, there are a growing number of national initiatives designed to address campus stigma, including the Jed Foundation’s [Half of Us campaign](#) and [The College Toolbox \(TCP\)](#) project of the larger national anti-stigma campaign Bring Change 2 Mind (BC2M). Campus-based student-led organizations such as Active Minds and NAMI are also working to challenge campus stigma.

Additional information on disability-based discrimination and harassment (and associated grievance processes) can be found in the Toolkit’s Legal Troubleshooting module.



3

Back to School Toolkit: An Introduction & Orientation for Families

INTRODUCTION

Psychosis very often emerges during the years in which young or emerging adults are most likely to be enrolled in postsecondary education (including community college, university and graduate school). Unfortunately, many postsecondary institutions are not fully equipped to support students diagnosed with a psychotic disorder and, to date, guidance specifically tailored to parents and family members of students with early psychosis has been largely non-existent.

This introduction and orientation is one component of a set of resources focused on supporting students with early psychosis in institutions of higher education. This Toolkit is broken up into multiple modules that include guidance materials, factsheets, and legal troubleshooting. Some modules target specific audiences (such as students, parents, or campus staff) while others were designed for multiple groups or a general audience.

The Back to School Toolkit was developed and supported by individuals with first-hand experience navigating college after a first break, alongside experienced early psychosis clinicians and educational and legal specialists. We hope that you will find the information included helpful.

Orientation

The goal of this orientation module is to introduce and explore a handful of ‘big picture’ issues. Other modules in this Back to School virtual resource package address such topics as academic accommodations and legal troubleshooting. **This section covers:**

- [Readiness to attend an institution of higher education](#)
- [Advance planning & campus privacy issues](#)
- [Big picture career development](#)
- [The importance of patience, perseverance and hope](#)

Is my child even ready for school?



Parents and family members frequently express concerns that their loved one might not be ready to start (or return) to school. Such worries are often compounded when the school the student attends (or wants to return to) is in a different region or state, possibly without access to a local specialty early intervention program.

Ultimately, of course, each individual, and each scenario, is unique. Ideally, family members, the affected young person, and trusted clinicians would carefully weigh the pros and cons of different possibilities: starting school part-time versus full-time; attending a campus close to home versus out of the region (or state); balancing “easy” versus more challenging courses. A list of generic risks and benefits is included in Table 1.

“My son keeps telling me he wants to go back to college, but it’s hundreds of miles away in another state and all his clinicians are here... I don’t want to tell him he can’t go, but I’m also extremely worried about everything that could go wrong. I don’t want to set him up for failure.”

-Parent of a young adult

Table 1.

Decision Point	Pros	Cons
New School Out of the Area	Gives the student a chance to start over	Need to find and establish relationships with new & unknown clinicians and providers
	Successfully living independently (e.g., in a dorm) can increase confidence and sense of normalcy	Student may have no existing support network in the area; private insurance may not cover remote providers
Returning to School Away from Home	Student may have friends, mentors and an established support network back at school	If the school was where an initial break occurred, returning may trigger difficult memories and there may be enduring impacts on relationships with other students, staff and faculty; if the student was near the end of school when the break occurred, friends may already have graduated and the student may feel isolated
More vs. Less Competitive School Environment	Some young adults (including students with psychosis) thrive in high-expectation environments	Others may find that the stress and pace of a competitive academic environment pushes them over the edge
	The psychological impact of giving up on dreams and aspirations (e.g., attending a very competitive school) can be devastating	Over-reaching prematurely and then failing or experiencing a significant set-back can also be psychologically devastating
“Difficult” vs. Easier Major or Program	As above, the impact of giving up on dreams/aspirations can be profound	As above, over-reaching can also very negatively impact the student
	Challenges and a lot of work, especially in an area the student is passionate about, can actually help the student focus and concentrate, and keep his/her mind off other things going on (including symptoms and associated fears and worries)	If the motivation is no longer there (or the student feels too demoralized), a heavy workload may be more harmful than helpful

Concerns about Stress and Relapse. Family members may also worry about “stress” in a more general sense. These concerns often stem from material or psychoeducation focusing on the “stress-diathesis” hypothesis of psychosis/schizophrenia, namely that people may be predisposed to develop psychosis but that it only occurs if certain socio-environmental triggers (or stressors) are in place. Exacerbations or relapses are also often framed in terms of discrete stressors. Although helpful in many ways, this general model can also have unintended negative consequences. First, it’s important to understand that what constitutes ‘stress’ is highly subjective. For one young person, taking a full load of high pressure courses might be stressful, but for another, it may alleviate the stress that would result from sitting alone in her room all day, ruminating about how messed up her life has become and worrying about the future. For another, even intense coursework might not be especially stressful, but the challenges of navigating campus social life (or dorm life) would be. It is important to not assume that any specific thing, in and of itself, constitutes an automatic stressor, but instead to think more broadly and individually about stressors and triggers and do everything you can to understand where your loved one is coming from.

—“I’m not giving up on anything, but I feel like the best thing for me right now is staying closer to home, and not taking on too much all at once. I feel like it’s better to re-build slowly and not disrupt the relationships I’ve built with the (early intervention team)....”

—“My parents don’t want me to go back to college out of State... I know this is because they love me, and are worried, but I think they’re being over-protective. All my friends are back there, and...really...my life. If I give up on the things I was doing before, I’m afraid that everything will change. It’s really important for me to stay on the same path.”

— **Two different views from students with first episode psychosis**

Parental Guilt & Anxiety. As a family member, it can be difficult not to feel a sometimes overwhelming sense of responsibility for what might happen to your child or loved one. These feelings are normal and natural. It’s far from easy to navigate the rollercoaster of emotions you’ve likely been feeling since your child’s first break: fear, anger, sadness, anxiety, self-blame, confusion and uncertainty.

What Your Child May Be Feeling. Not unlike other young adults, your student is likely experiencing conflicting feelings about dependence versus independence, further complicated by the impact of psychosis on his or her identity and sense of autonomy. Your child is also much more influenced by your reactions and feelings (or projected feelings)



than you may realize. In conversations about family relationships with young adults with recent psychosis, one frequently hears speculations (and concerns) about likely parental disappointment, perceived embarrassment (“I know my dad hasn’t told my uncle what happened and I think it’s because he’s ashamed”), and comparisons with siblings (“I’m sure my parents now think that my sister’s the family success story, and that there’s no hope for me”). Young people may not share these feelings or interpretations with their parents at all, and instead feign nonchalance or indifference. Your child may also be feeling considerable confusion stemming from the impact of developing psychosis on his or her sense of autonomy and independence. Entering into more intensive treatment (whether with a solo psychiatrist or therapist or an entire early intervention treatment team) can introduce young people to

a “patient” or “client” role that may feel both oppressive and protective. These experiences can further complicate the very normal young adult task of establishing new and different relationships with the ‘parental’ or ‘caregiver’ figures in their lives.

Advance Planning & Campus Privacy Issues

As you prepare for a child or family member to return to (or start) school, one of the best ways to assuage your own worries and anxiety is to do as much background reading and research on his/her institution (counseling center, institutional policies, and community resources) as you can. Students and their parents should investigate the services that are available at the counseling center and in the community. For example, rural schools likely will not have as many counseling services available in the community, while urban centers will probably have more options. Students and their families may want to:

- **Examine counseling center resources.** Some institutions will have a very robust counseling center which includes 24-hour on-call psychiatric services, psychologists, support groups, hotlines, mobile support, a wellness center, therapy dogs, Active minds or NAMI on Campus chapters, among other supports. Others have weeks-long waiting lists, few providers and a very high student-to-staff ratio. Some have up-to-date extensive referral lists. Others simply refer students to community providers.

- **Request the student-to-(full-time) clinical staff ratio.** The International Association of Counseling Services (IACS) has recommended minimum staffing ratios of one full-time professional staff member (excluding trainees) to every 1,000 to 1,500 students, depending on the services offered. The average ratio of mental health professionals to students as reported in the National Survey of Counseling Center Directors (2014) is 1 to 2,081 (note: the figure is elevated because of the inclusion of two year school ratios). Students at smaller schools generally having much better ratios.
- **Give as much attention to investigating the available counseling center resources as the dorms, extracurricular activities and athletic facilities.**
- **Talk** to the counseling center, students, and student organizations to learn more about the available services.
- **Examine the institution's website.** Families can also learn a lot from exploring the postsecondary institution's website and observing whether it's geared toward current or prospective students, and whether information about counseling and support services are easily accessible.
- **Talk to school administrators and review institutional policies.** Some institutions have very rigid policies and harsh codes of conduct.
- **Examine institutional policies regarding leaves of absence** (personal and medical), incompletes, adding and dropping course, and accommodations, tuition reimbursement.
- **Note the transparency of institutional policies;** some institutions have very transparent policies, including policies regarding involuntary leaves of absence. Others do not. Because a postsecondary institution does not have a published policy regarding involuntary leave or withdrawal, do not assume that they do not impose involuntary leaves.
- **Explore** the postsecondary institution's health insurance and any tuition reimbursement policies.
- **Read the institution's student newspaper** to explore current issues.

In addition to background research, encourage your child to work with you or his/her providers on an "advance plan" and sort through the campus and clinical privacy issues that are likely to affect you in one way or another. Further information on campus services and policies can be found in the Toolkit's Guide to Campus Services and Administrative Departments, including questions that family members might ask and explore to better understand specific postsecondary institutions. More detailed information on psychiatric advance planning can be found in the Student Introduction and Orientation section. Finally, the Toolkit includes multiple other information briefs and modules that you may find helpful (or simply encouraging), including guidance on accommodations and "Voices of Success."

NAVIGATING PRIVACY LAWS ON CAMPUS

Privacy laws and policies are often a significant source of frustration (and sometimes anger) for family members. Several privacy laws are relevant in the campus setting including the Family Education and Privacy Rights Act (FERPA), state mental health and privacy laws, and professional ethics and licensing standards. A more thorough discussion of these privacy laws and protections in the campus setting is included in the legal troubleshooting module.

Generally speaking, information shared with treatment providers is confidential and will not be shared with family members without a student's consent unless there is a substantial and imminent threat which the family members can address. In contrast, postsecondary administrative officials and faculty members can share information with family members without a student's consent if there is a health or safety emergency, or if the student is dependent for federal tax purposes.



In addition, school staff *may* (but have discretion not to) disclose information to parents that is not part of the student's formal educational record, but rather based on their personal observations (or on what they have heard from other staff, faculty or students). However, while postsecondary institutions may disclose information regarding a student, they are not required to do so, and often chose not to. In addition, campus faculty and administrative staff are not always aware that they can do so, and hence may operate under the assumption that they cannot disclose anything to parents.

Keep in mind that even if school administrative staff can (and want to) speak with or contact parents or family members, they do not always have access to the necessary contact information (i.e., names and numbers). While it is always recommended that parents not “go behind their child's back” and contact college staff or instructors without their knowledge, the more individuals on campus who know (or at least are able to contact) the parents in the event of problems, the better. This might include some of the student's friends, a departmental advisor or mentor, and key administrative staff. Also keep in mind that the student is generally responsible for entering (and for the accuracy of) any official emergency contact information contained in their formal records.

A campus staff member or official (but not medical provider) who hears or observes worrisome information that clearly does not constitute an imminent threat but is nevertheless cause for concern is not prohibited by FERPA and can freely contact parents, security personnel or law enforcement officers, and campus counseling staff, among others. Again, the ability of staff or providers to contact parents or family members, whether in an emergency or non-emergency situation, depends on the availability and accuracy of any contact information.

Release Forms

Whether or not there is an emergency, it is always a best practice—if the student consents—to sign and file formal release forms as soon as he or she starts seeing a new provider and/or starts school. The student can choose to limit the information that providers or staff can communicate, and can also impose a time limit on his or her consent. Even if your child or family member has no active plans to utilize campus health or campus counseling services, filing a release form with them is a good idea in case of a future emergency or incident in which campus providers might become involved and/or respond.

We suggest that families engage in conversations about communications and privacy well in advance of returning to school. Such discussions should follow the adult-student's lead while collaboratively considering the pros and cons of easier communication in the event of an emergency.

Career Development: The Big Picture

One often thinks about postsecondary education in terms of degrees and certificates: AA's, BA's, and so forth. Research on young adulthood and career development, however, consistently affirms the role and importance of postsecondary participation and engagement (see sidebar) for reasons that go well beyond degrees. Perhaps most importantly, campus *social* experiences can be critical to the development of a young adult's relational skills and social capital (i.e., the social assets and networks that can ultimately play a determining role in future career mobility and civic involvement). From this perspective, supporting your child or family member in college is not just about helping them pass courses or accrue enough credits for a degree, but rather enabling and facilitating a critical period of personal and social exploration, growth and network building.

Beyond Courses: Social & Personal Development in Postsecondary Settings

Expand social networks and develop an expanded array of relational skills (e.g., with other students, co-workers, advisors or supervisors, and mentors);

Opportunities to date, 'hook up,' and build romantic and/or sexual relational skills;

Participate in unpaid (or low-wage) but skill and resume building internships, practicum and volunteer positions;

Explore different career paths and possibilities without the burden of debts and/or family responsibilities and dependents that become increasingly common in later adulthood;

Develop interests, hobbies and activities that may not turn into a career, but enrich life and contribute to active community participation and social integration.

Concretely, this means that activities like partying, dating (or “hooking up”), joining a sports team, engaging in extracurricular activities, pursuing an internship or just taking the time to hang out with friends may be just as (or more) important to a young person’s future than the grades he or she gets. These sorts of age appropriate “normalizing” activities may be even more important for young adults with psychosis. (More than one parent has noted that what ultimately ‘saved’ their child was developing a strong and supportive romantic relationship.)

Parents Looking Back

“A few weeks ago I actually found a letter I’d written to my sister about a year after [my son] was first diagnosed. It’s almost hard for me to believe how depressed and hopeless I felt then. Things are so different now—he went back and finished college, is working and in a steady relationship. I feel blessed but also want other parents to realize that no matter how bad it seems, things can really turn around. You should never give up.”

“Is [my daughter] doing what we originally expected? No. But she’s finished her BA [at a different school] and has discovered other strengths that she didn’t know she had and we didn’t know she had. She’s a beautiful person and really, at the end of the day, my hero. For a long time I thought I needed to be strong for her and now I realize that maybe it’s always been the other way around.”

Patience, Perseverance & Hope

Psychosis is a very complicated—and variable—experience. Some young adults recover swiftly following a first episode, while others struggle for many years before getting back to a place where they can pursue their dreams and goals. There’s really no “average” or “normal” when it comes to these trajectories: every individual is unique. And while it’s wonderful that some young people almost immediately get back on their feet, a delayed recovery is not a good reason to give up or to conclude that a particular individual simply “has a worse course” or “needs to adjust to different expectations.” It may be hard to believe, but even the most seemingly intractable symptoms—what appear to be serious cognitive deficits, disorganization, or negative symptoms—can subside. While we know a fair amount about recovery, big pieces of it remain a mystery.





4

Campus Mental Health Services & Administrative Departments: A Guide for Students and Families

While every campus is different, most postsecondary institutions share similar departments of student services. All educational institutions that receive federal funds must comply with laws such as Section 504 of the Rehabilitation Act of 1973 and the Family Education Rights and Privacy Act (FERPA). Postsecondary institutions must also comply with the Americans with Disabilities Act (ADA). This module lists key offices and policies, along with questions to consider asking in preparation for (or in the process of) transitioning back to school.

Specifically, this module covers:

- [Dean of Students Office](#)
- [Office for Students with Disabilities](#)
- [Campus Counseling/Student Health](#)
- [Office of Residential Services](#)
- [Office of Institutional Equity/Grievances & Complaints](#)

Dean of Students Office

Broadly speaking, the mission of the Dean of Students Office (DSO; sometimes known as the Dean of Student Affairs) is generally to provide supports, resources and advocacy specifically for students and their families (rather than faculty or staff). Many DSOs refer to themselves as the “single point of contact” for students and families in times of crisis or transition. Over the past decade, a growing number of DSOs have begun to hire social workers or service coordinators dedicated to assisting students with more intensive physical, medical or psychiatric needs and disabilities. DSOs also frequently serve as the primary coordinating body for new students seeking disability-based academic accommodations and/or counseling services for the first time. Some other roles that the DSO can play include:

- Managing the school’s academic and nonacademic misconduct systems;
- Coordinating emergency services/emergency response for students experiencing a mental health crisis;
- Supporting student transitions, including leaves of absence and/or withdrawal from courses;
- Overseeing or advocating for students in the context of disciplinary hearings and actions, including student misconduct, temporary suspensions, involuntary leaves of absence and dismissal;
- Strengthening positive campus climate and respect for diversity through programs and initiatives that may include faculty, staff and/or campus-wide trainings on mental health and/or disability; and
- Providing referrals to additional services and supports, both internally and in the surrounding community.

Questions to Ask about the Dean of Students Office (DOS):

- What specific services does the DOS provide for students with a psychiatric disability?
- How, and under what circumstances, does the DOS interact with parents and family members? In case of an emergency, how and when are family members notified?
- What information can the DOS Office provide with respect to campus policies concerning hospitalization, medical leave, and response to student crisis situations?
- Does the DOS oversee a process allowing students to grant legal permission for DOS staff to communication with families under particular circumstances?
- Is the DOS aware of additional supports for students, such as campus clubs focused on mental health awareness and/or peer support?

Office for Students with Disabilities

Virtually every postsecondary institution operates a dedicated Office for Students with Disabilities (OSD). The primary duty of such offices is generally to process and approve academic accommodations in compliance with the Americans with Disabilities Act (ADA) and similar federal and state statutes and policies. Like other campus services, the scope and quality of OSD services varies enormously from institution to institution. Some OSDs employ specific staff with dedicated expertise in psychiatric accommodations, for instance, while others may not employ a single staff member with any background working with more severe psychiatric disorders. While still rare, a handful of OSDs maintain dedicated support initiatives focused specifically on meeting the needs of students with psychiatric disabilities (beyond individual accommodations), and others organize peer-to-peer support groups focused on study skills and academic troubleshooting. One of the biggest challenges students with psychosis may face is a lack of understanding on the part of OSD staff as to the nature and impact of symptoms associated with psychosis, and potential accommodations (beyond those more generically provided to students with an array of physical or learning disabilities, such as extended testing time). An overview of the standard accommodations process is provided below. Advice regarding navigation of the disability accommodations process and maximization of potential benefits is covered in the academic accommodations section and the suggested accommodations factsheets.



THE ACADEMIC ACCOMMODATIONS PROCESS

- 1. Initiation of Request.** Student initiates a request for accommodations, typically by contacting the OSD directly.
- 2. Medical Documentation.** OSD staff typically provide a written policy detailing the school's requirements for medical documentation of the student's disability, and often provide a template for providers. In general, OSD staff will not discuss accommodations until documentation has been provided.
- 3. Discussion & Approval.** Schools may or may not require that medical documentation include specific recommendations for accommodations. Regardless, medical documentation is often used to contextualize dialogue with the student about the accommodations he or she might need or want for different courses. In addition, students may be asked about policy modifications, such as permission to register for courses ahead of other students, or to be counted as a full-time student for financial aid purposes even if taking a reduced course load.

- 4. Accommodations Letter.** After OSD staff and the student agree to specific accommodations, the student is typically provided with a letter that can be provided to faculty or other staff, explaining the accommodations that have been approved without listing a specific diagnosis or disability. However, note that some OSD offices may encourage students to involve faculty or instructors directly in the accommodations decision-making process, and/or students may be able to request such involvement.
- 5. Instructor Notification & Discretion.** The faculty/staff retain discretion as to whether or not the requested accommodations are “reasonable” in the context of course expectations and required (essential) competencies. In practice, however, it is extremely rare for faculty or instructors to challenge more widely accepted accommodations.
- 5. Exercising Requested Accommodations.** In most cases, the requested modifications will begin immediately. Depending on the type of accommodation, the student may need to remind the instructor of the accommodation at a later time.

Questions to Ask about the Office for Students with Disabilities (OSD):

- Does the OSD have staff with specific expertise in psychiatric disabilities? What about psychosis: has the OSD worked with students diagnosed with a psychotic disorder before?
- How, and under what circumstances, can family members get involved in the accommodations process or assist in advocating for accommodations on behalf of their loved one?
- What is the process or protocol for obtaining accommodations that may be needed in emergency or crisis situations, for instance, in the instance of an unexpected relapse or hospitalization?

Campus Counseling Center/Student Health

Almost all postsecondary institutions support campus counseling centers (CCCs), though in some cases these may be embedded within broader student health services or attached to academic advising offices or divisions. The intensity and duration of CCC services varies. Some CCCs provide only short-term counseling, limiting students to a set number of sessions, while others provide ongoing counseling and/or therapy to students who meet certain criteria. A growing number of CCCs (and/or broader campus health centers) employ psychiatrists or nurse practitioners to provide medication monitoring and management. Many CCCs also provide group or couples therapy, as well as more informal drop-in groups or wellness services (such as a mindfulness group). Additionally, CCC staff may sponsor student-driven groups or initiatives such as Active Minds and NAMI on Campus (see Resources).

As with OSDs, CCCs vary tremendously in their expertise and capacity with respect to psychosis. For instance, some CCCs may employ staff therapists or counselors with considerable experience working with more serious psychiatric diagnoses while others may consider conditions such as psychosis “outside their scope” and refer all such students (and their families) to mental health providers or agencies in the community. It is worth remembering that even if students do not engage with the CCC for ongoing therapy or services, in the case of a mental health crisis or emergency, other staff or administrators may still contact (and involve) CCC staff as first-line responders.

Questions to Ask about the Campus Counseling Center (CCC):

- What are the CCC's policies with respect to therapy and medication management? If the CCC does not provide ongoing services, what relationships does it have with community providers?
- Does the CCC employ staff with specific expertise in psychosis? What is the CCC's general level of awareness and understanding with respect to psychosis, including acute psychotic episodes or emergencies?
- What services are available at the CCC? Are there psychiatrists on staff? Is there a hotline, or are on-call services otherwise available 24 hours a day (or does the school rely on police and ambulance services for after-hours crises)?
- What events are held during stressful times, such as finals and mid-terms – are there stress reduction or meditation classes, yoga, therapy dogs?
- How, and under what circumstances, might the CCC be contacted by campus faculty or staff about a student? What procedures would be followed/what might happen to the student?
- What role, if any, does the counseling center play with regard to leaves of absence, especially involuntary leaves? What information does or might CCC staff share with other campus staff or administrators?
- Under what circumstances would the CCC contact family members? Is there a process that enables students to grant express permission for family communication about certain issues or under certain circumstances?
- Does the CCC sponsor any groups or initiatives that might provide helpful additional supports to the student, regardless of whether he or she receives ongoing care through the Center?

Office of Residential Services

Offices of Residential Services (ORSs) generally oversee the administration and operation of student housing services, including dormitories, student apartments and, in some settings, related dining services. Residential services typically enforce codes of conduct that are independent from (or augment) broader campus codes of conduct that apply to both residential and non-residential students. Some ORSs also maintain an internal judicial process designed to investigate, resolve and enforce residential student conduct policies. ORSs may also sponsor a variety of programs and initiatives aimed at promoting successful adjustment to campus life, sense of community, and student leadership. Most dorms, though typically not other forms of student housing (such as individual apartments), have resident advisors or assistants (“RAs”) that offer support and services to students and also participate in disciplinary conduct procedures.



Questions to Ask about the Office of Residential Services (ORS):

- How much background or understanding do ORS staff have with respect to significant psychiatric disabilities, as well as psychosis more specifically? Do residence assistants or other staff receive any regular training in mental health awareness and best practices for supporting students with mental health challenges?
- How might ORS student conduct policies impact a student with psychosis? If a student experienced a relapse in a residential setting, how would this situation be handled, and what policies or procedures might come into play?
- Are there any established policies with respect to disability-based housing accommodations? For example preferential placement, access to single rooms or quiet floors, ability to bring a therapy or support animal, and so forth.
- What procedures are in place for communication with family members, both in the event of an emergency and lower level concerns (for example, marked change in behavior such as self-isolation that residential staff might notice)?

Office of Institutional Equity/Grievances

On many campuses, a single office (most often referred to as an Office of Institutional Equity) oversees the investigation of complaints and the grievance process for any form of discrimination or harassment. In some settings, however, other offices may take on targeted responsibility for complaints falling within their specific domain: for example, some student disability offices oversee the investigation of complaints related to disability-based discrimination and/or harassment, as well as other types of violations of the Americans with Disabilities Act. A separate office may also investigate discrimination and harassment experienced in the context of student employment. As a general rule, however, both campus OIEs and Dean of Students Offices should be able to quickly redirect students and/or families to the appropriate process and/or office.

Family members should note that, in addition to internal complaints, students can also file federal grievances with the Department of Education's Office of Civil Rights (OCR), or the Department of Justice (if related to experiences as a student) or the Equal Employment Opportunity Commission (EEOC) if the student is an employee. Students may also be able to file complaints in a state's human rights office for violation of state anti-discrimination laws. In addition, and depending on the circumstances, students and/or families may want to seek outside legal advice and services.

Note that complaints to the Department of Education's OCR must be filed within 180 days of the allegedly discriminatory act. State statutes will have other statutes of limitation. OCR may grant a waiver of the 180-day filing requirement if the student filed a complaint with another enforcement agency or filed an internal grievance and the OCR complaint was filed within 60 days after the other investigation or grievance concluded. If a student files an internal grievance, OCR may not conduct its own investigation; instead, it will review the results of the internal grievance and determine whether the student received a comparable resolution process under comparable legal standards. These possible routes and related issues are discussed in greater detail in the Toolkit's Legal Troubleshooting module, and additional resources are listed in the Resources section at the end of the Toolkit.

Questions to Ask about the Office of Institutional Equity (OIE):

- Does the school's OIE or similar office engage in any proactive outreach to help reduce stigma, discrimination and/or harassment based on psychiatric disability?
- Are there clear procedures in place for addressing complaints related to disability-based rights, including accommodations, and who or what office(s) are involved?
- Under what circumstances can a family member initiate a complaint, and what policies govern communication with family members?



5

Addressing the Impact of Psychosis: A Guide to Academic Accommodations and Self-Help for Students & Families

Provision of disability-based accommodations is mandated by federal anti-discrimination laws and typically administered by a dedicated campus disability services center or office. The general purpose of accommodations (whether in school or work settings) is to “level the playing field,” allowing persons with disabilities equal access and opportunities. Unfortunately, considerable controversy remains as to how well persons with psychiatric disabilities are served by standard accommodation policies and practices.¹ In conversations with students with psychosis, one often hears reports of interactions with disability office staff who are under-equipped to recommend accommodations specifically tailored to students with psychosis and who have little understanding of the impact of both psychotic symptoms and societal reactions (e.g., stigma, prejudice). Many disability services staff lack formal training on significant psychiatric disabilities. Students also frequently report barriers to accessing or fully utilizing formal accommodations. Some decide that the generic accommodation options they’re offered would not help them, and therefore give up on the process altogether.

The goal of this guidance module is to: walk students (and families) through the disability accommodations process; discuss the broader impacts of psychosis on academic functioning; and suggest specific accommodation possibilities, along with examples of where and how each accommodation might help.²



“First I went to the school disability office and asked if they could help me. All they did is pass me a list of standard accommodations and not one of these seemed relevant to me. They suggested that I get some suggestions from my provider. So then I talked to my psychiatrist and he had absolutely no idea what to tell me. He asked me for my opinion and in my head I was thinking “isn’t someone supposed to be providing me with guidance on this? How can I possibly know how to accommodate these challenges?” I considered just giving up for a long time and didn’t actually go through with any requests. Then a couple of years later I finally did, but I’m still not sure if these were the most helpful accommodations. I’m still not sure why there isn’t more guidance available.”

—‘Jenny’

The Disability Accommodations Process

With a few variations, the disability accommodations process generally proceeds as follows:

- **First Encounter.** When a student shows up at a campus disability center, staff will typically provide general guidance on accommodations, list(s) of standard accommodations and a form for the student to take to a provider to document disability and (in most cases) endorse or recommend specific accommodations. Some universities require (or strongly prefer) that accommodations be secured before, or very early in the course of, a given academic term.
- **Medical Documentation.** Once the student decides to pursue accommodations, he or she meets with his/her provider (often, but not necessarily, a psychiatrist) to discuss the impact of the student’s psychosis (the functional limitations) and potential accommodations. The provider then creates a disability documentation letter which typically includes a formal diagnosis, description of the impact on the student’s functions, and a list of suggested accommodation strategies that the provider sees as justified on the basis of the student’s disability. The provider then either gives the student the official signed disability documentation letter or form, or sends/faxes the letter directly to the student’s disability services office.
- **Follow-Up Meeting with Disability Staff.** The student then meets with a disability center staff member to finalize specific accommodations. In some cases, disability center staff will encourage a more interactive process in which specific faculty or departmental representatives are also involved in order to ensure their input in determining accommodations that will actually allow the student to succeed. [In the authors’ experience, this is relatively rare but not unheard of, and students should feel free to request a more interactive approach if it would be helpful.]

- **Accommodations Letter for Faculty/Instructors.** The disability center then provides the student with documentation for instructors or other staff that lays out the specific approved accommodations without disclosing any information on the exact nature of the disability or diagnosis. The student presents this documentation to individual faculty or staff. In most cases, the accommodation is accepted and followed, but the faculty/ staff person also has the opportunity to contest the accommodation(s) on the grounds that it would either cause “undue hardship” or compromise the “essential elements” of a course or curriculum. If faculty/staff are involved earlier in the process, these concerns may be expressed earlier on in the process.
- **If the Instructor/faculty Contests the Accommodation:** Typically a follow-up meeting involving the student, disability center staff, and instructor will take place. Depending on the exact scenario, the disability center staff might insist that the instructor follow the suggested accommodation or collaboratively explore alternative accommodations. Students can file a grievance or appeal if their request for accommodations is denied. For more information on contested accommodation requests, see the Legal Troubleshooting guide.

‘Undue Hardship’ & ‘Essential Elements’ Explained

Undue Hardship: “action requiring significant difficulty or expense” when considered in light of a number of factors. These factors include the nature and cost of the accommodation in relation to the size, resources, nature, and structure of the school’s operation.

Essential Feature: the essential outcomes that students must demonstrate in order to successfully complete the course – consistent with the overall purpose of the course, essential elements are the skills, knowledge, principles and concepts that a student must master.

WHAT CAN GO WRONG

Unfortunately, students can and frequently do encounter multiple challenges negotiating the above process. These include:

- **Untrained Disability Center Staff.** Staff may have little or no background on psychosis or significant psychiatric disabilities and not be especially well-equipped to provide guidance or advice.
- **Inadequate Generic Suggestions or Guidance.** The list(s) of accommodations provided to the student may not seem relevant or helpful as accommodations for psychosis.
- **Disability Documentation from a Provider that the Student Does Not Know Well.** Particularly for students who have moved to a new city or area for college and hence have only recently established a relationship with a provider or psychiatrist, he or she may have little information on which to base specific recommendations. These challenges may be compounded when a student, having previously been treated closer to home, is not actively experiencing symptoms.

- **Underprepared Providers.** In many cases, providers themselves may lack familiarity with the accommodations process or with the range of possible accommodations. The provider might also lack an understanding of what accommodations might help students in programs with which the provider has limited familiarity (for instance, an architecture or engineering program).
- **Unwilling Faculty or Staff.** Finally, disability center staff and/or faculty/instructors may claim that a given accommodation represents an undue hardship and/or compromises an essential element of the course or program.
- **Stigma about Psychosis & Mental Illness.** Unfortunately, students frequently report either fears that they will be judged for requesting accommodations and/or actual experiences of such discrimination. In addition, students may impose judgmental attitudes on themselves, concluding that psychiatric accommodations are a sign of weakness, or would prove that they are unable to succeed on their own. Students who are or have been successful academically are often the most susceptible (see side quote).



“So...yeah, even though I study psychology, and understand self-stigma and the rights and rationale behind accommodations, it’s taken me a really long time to formally request anything. Before I developed schizophrenia I was a star student and it’s been incredibly difficult for me not to see accommodations as a sign of failure. I’ve also always worried that faculty who see me as “disabled” will be unwilling to write me strong letters of recommendation. I feel like it compromises my whole future.”
—‘Chen’

ACCOMMODATIONS SELF-ADVOCACY

Not all the challenges students may encounter in an attempt to secure accommodations are easily fixable. To reiterate earlier advice, we nevertheless strongly encourage students (and their friends, family and clinicians) to do everything possible to explore and advocate for effective accommodations. In some cases a formal complaint or litigation may nevertheless be required; see Sections 4 and 6. The remainder of this section focuses on describing a range of specific accommodations. It may be helpful to take this guide (or a copy of the relevant lists) to meetings with disability center staff and/or providers.

THE TOOLKIT'S APPROACH TO ACCOMMODATIONS

In order to construct the accommodations lists and suggestions contained in this guide, the authors consulted with multiple sources and advisors, including students with psychosis, researchers and clinicians, the existing empirical literature and available guidance. This document approaches accommodations with the idea that it's not always the students' "symptoms" *per se* that are the core problem, but rather the triggers or the stressors underlying the symptoms. For example, a student's voices ('auditory hallucinations') might increase significantly prior to and during oral presentations, but the actual "problem" that needs to be addressed is the social and performance anxiety the student feels about speaking, rather than the voices themselves (see figure).



In addition, students might experience significant side effects from medications (fogginess, fatigue, inability to stay awake in class) or symptoms that are secondary to the student's other experiences (such as depression stemming from the impact psychosis has had on the student's life so far). It's always important to think through accommodations, modifications and extra supports that will help address all these challenges, not just "psychosis" narrowly defined (and to communicate this as clearly as possible with staff, providers or instructors involved in the accommodations process).

FORMAL VS. INFORMAL ACCOMMODATIONS

While the ADA itself technically requires that schools follow a transparent process for 'official' accommodations, many students report that they find it more helpful to work directly with a trusted advisor and/or departmental mentor (or a very understanding administrative officer) to craft an informal plan for accommodations and supports (i.e., not involving disability services or a formalized accommodation process). Faculty and students who have engaged in informal accommodations often report that they chose to take an informal route because it allows for the greatest flexibility and responsiveness to needs that might arise suddenly. Analogously, faculty and staff often "accommodate" students in situations not involving disability (such as the death of close family member, difficult family circumstances, medical issues that do not qualify as disabilities, and so forth).



“Honestly when a student has a very stable and straightforward disability like being blind or deaf, I think the formal accommodations process works fine. This has often not been my experience with psychiatric disabilities. Student’s mental illness-related problems and symptoms are often much more complex and variable, and can often get worse very suddenly and unexpectedly, or a new assignment can come up that they find challenging in a way neither of us could predict. Under such circumstances the time and bureaucracy involved in working with the disability center seems really counterproductive and I’d rather just work directly with the student to support his or her needs.”

— **University Instructor**

Students in particular types of programs or internships might also need “guidance” more than specific modifications—for instance, a Master’s counseling student in a clinical internship might need extra guidance on how to navigate his or her clinical work in light of episodic symptoms, and such “extra guidance” is not especially well suited to a formal accommodations request.

Note, however, that the Office of Civil Rights (OCR) and courts have found that accommodations must be documented. A postsecondary institution can refuse to grant a student’s request for an accommodation that is not specifically recommended in the student’s documentation. If a student challenges the denial of accommodations, OCR and courts will look to see that the student is registered as a student with a disability and followed the postsecondary institution’s formal accommodation procedures. For this reason, it may be the smartest strategy to seek formal accommodations and get a documentation letter in addition to seeking informal accommodations with willing professors and supervisors.

Symptoms, Side Effects & their Academic Impacts

Unlike many physical and sensory disabilities, which impact people in relatively stable and consistent ways, the symptoms and challenges associated with psychosis can fluctuate significantly, appear and disappear, or only become a problem under very specific circumstances.

Paranoia and Feelings of Persecution. Feelings of paranoia are often triggered by specific people, places or circumstances. For instance, you might feel particularly fearful of just one of your instructors, but not the rest; feel that a group of students in just one of your classes keeps whispering about you; or feel anxious about a particular classroom because of its technological set-up or the sounds that the fans or projector makes.

► IMPACT

- These feelings may make it difficult to concentrate, or difficult to physically attend classes or engage with particular instructors or peers.
- The fact that feelings of paranoia may only arise with respect to particular people or settings may make the impact on you harder for others to understand.

Feeling Like Things Aren't Real. At times the world and events may feel strikingly “off,” disconcerting or fake. People's faces might not look right, or it may feel like something is very wrong with the world even if it's not clear what is wrong. You might feel everything is staged, or that you're trapped in a parallel universe.

► IMPACT

- These experiences can be frightening, distracting or make it difficult to maintain attention or concentration.
- You may feel like you can't relate to other people, or that it's difficult to engage with instructors or other students on projects or in class discussions.

Voices & Other Perceptual Experiences. Voices may be constant or triggered by specific activities, situations or incidents—such as being in a crowded room, feeling unsafe or feeling judged or at risk of being judged. Your voices might talk constantly, get worse when they're around lots of people who are talking, or only let up when listening to music. You might also feel like someone or something is sending you messages, even though you don't “hear” them the way one would hear a sound. You might also feel strange sensations (like you're being touched or like things are crawling up your legs or arms). When you touch things (like a keyboard or the arm of a chair), the surface might feel strange. Or you might feel like part of your own body is merging with objects that you touch.

► IMPACT

- These experiences can be frightening, distracting or make it difficult to maintain your attention or concentration.
- You may not be able to understand what other people are saying if the voices are loud or get worse during lectures or conversations.

- Voices may say things, or you might receive messages, that are very negative or derogatory. For instance, they might mock you, tell you you're stupid, or warn you that you're going to fail a test or give a bad presentation.
- You may feel very isolated because your experiences are so different from those of the students and people around you.

Finding Meaning & Connections Where Other People Don't.

You might find yourself noticing (or feeling preoccupied with) hidden meanings or connections that others don't seem to notice. For instance, you might think a lot about all the different things that a single word can indicate, or notice connections between things that you find meaningful but others see as random coincidences. These experiences might be positive, neutral or negative. You might also feel preoccupied by particular themes or books, such as a particular spiritual tradition, a work of philosophy or book of poetry.

► IMPACT

- These experiences may make it more difficult to concentrate on courses or academic work; you might find yourself caught up in your own thoughts or observations and have a more difficult time following lectures or completing assignments.
- Other students or instructors may not understand your interests or experiences, and so you might feel isolated or misunderstood.

Depression & Demoralization. The challenges associated both with symptoms, as well as the stigma and prejudice you may encounter in other students and staff, can be very demoralizing. You might also feel like you'll no longer be able to accomplish the things you wanted to, major in what you wanted to, or pursue a particular career.

► IMPACT

- You may feel like there's no point to school anymore and find it difficult to motivate yourself.
- You might be afraid of doing things (taking a difficult class, or pursuing an internship) that you think would "set you up for failure," and therefore you don't try.
- It might be difficult to do basic things like getting up in the morning, getting to classes on time, exercising or eating regular (healthy) meals.

'Lethargy, Fatigue & 'Fogginess.' Extreme fatigue may be connected to psychosis directly or stem from known side effects of medications. You may feel excessively sleepy or tired and have difficulty concentrating, or feel like you need to sleep twice as long as you used to (for instance, some students on medications like clozapine report needing to sleep 14-16 hours a day). Sometimes you might fall asleep in class. You may also find it difficult to think clearly or to concentrate.

► **IMPACT**

- Physical fatigue and lethargy can make it difficult to get to class on time and to stay awake and alert.
- If you end up nodding off in class this might lead to anxiety that other students or instructors will judge you or come to the wrong conclusions; you might also end up feeling more socially insecure.
- It might take you a lot longer to do things than it otherwise would. Sleepiness might rule out staying up all night to study for an exam, or sleeping only a few hours a night so that you can finish final papers at the end of the semester.

Memory Problems. Psychosis can affect memory, and you may find it significantly more challenging to memorize information for quizzes or exams. Some evidence suggests that retrieval is more impacted than encoding (i.e., information is effectively stored in your brain, but it's more difficult to access). For instance, you might in fact know someone's name and who they are, but not be able to recall it.

► **IMPACT**

- Memory problems can create significant difficulties with tests and assignments that depend on the memorization of facts or information.
- Strategies that previously worked for you may no longer work and you may need to come up with alternative ways of memorizing and recalling information, or spending much more time memorizing information.
- It might take you a lot longer to do things than it otherwise would and sleepiness might rule out staying up all night to study for an exam, or sleeping only a few hours a night so that you can finish final papers at the end of the semester.
- Courses requiring lots of memorization, such as core science classes and foreign language classes, may be particularly frustrating or difficult.

“I’m now a working scientist—I’ve completed my PhD—and am very successful in my work, but a lot of science courses, especially at the undergraduate level, revolve around rote memorization. After I developed schizophrenia, my memory was completely shot—I went from having a near photographic memory to failing exams because I simply could not pull names and information from my head, no matter how hard I worked. In reality, being a good scientist does not depend on an ability to memorize lots of facts—it has to do with deeper conceptual understanding and an ability to generate (and test) ideas and hypotheses...

I feel like my instructors need to ask themselves if rote memorization is truly “fundamental” to science coursework or if instead, by focusing so much on this, they’re screening otherwise very capable and even brilliant students. In my case, selective disclosure to key faculty was what helped me: they understood that what I had to offer was not tied to my ability to memorize facts, but rather my ideas and insight.”

— ‘Simon’



Attention & Concentration. Many of the symptoms of psychosis (listed above) can lead to greater difficulty concentrating on lectures, readings or assignments. Challenges involving attention may also stem directly from psychosis. In addition, fatigue and grogginess caused by medications can lead to difficulty concentrating and staying awake.

► **IMPACT**

- You might find that your attention has drifted off in the middle of a lecture or conversation and this may make it difficult to track what’s happening or to understand more complicated academic material.
- You might lose track of what instructors or other students are saying to you, and not know how to respond or feel embarrassed.
- More serious attention problems may make it difficult to work for long periods of time and you might need to take more breaks and plan extra time in order to accomplish the same things that you could have completed more quickly or efficiently before developing psychosis.

EXPERIENCING SIGNIFICANT CHALLENGES DOES NOT MEAN YOU CAN'T SUCCEED

For many students, it's difficult to read through lists of symptoms associated with psychosis, and descriptions of their impact, and not feel (further) demoralization. For most students, navigating psychosis is definitely not a cakewalk. At the same time, it's critically important to remember that individuals with psychosis do succeed in school, and succeed at the highest levels. See the Voices of Success brief for concrete examples (as well as inspiration and advice).

It's also worth reminding yourself that you may be able to address some of the challenges you encounter by developing new study skills and strategies. If older strategies don't work, that doesn't mean that your brain is now "permanently broken" or that there's no hope—instead it may just mean that you need to adjust the way you go about working, reading, writing, or memorizing material. Some suggestions are provided in the table below.

Additional or Alternative Work & Study Strategies	
General Strategies	<ul style="list-style-type: none">• Taking more frequent breaks & working for shorter and more concentrated periods• Exercise and good healthy eating and sleeping habits• Allowing more time for tasks• Alternating between different tasks at intervals to improve concentration
Writing Papers	<ul style="list-style-type: none">• Asking other people to read through outlines and drafts• Reading what you're writing out loud• Talking through your ideas with other people
Reading Assignments	<ul style="list-style-type: none">• Taking notes on key themes & ideas• Summarizing what you're reading as you go• Not trying to read too much at once• Taking breaks that include fresh air or physical exercise to improve concentration
Understanding Concepts	<ul style="list-style-type: none">• Finding two or more descriptions (or textbooks that cover) difficult concepts• Trying to put concepts in your own words• Visualizing the concept and drawing or sketching it using minimal words• Talking through concepts with other students or instructors

(Continued: Additional or Alternative Work & Study Strategies)

Additional or Alternative Work & Study Strategies	
Memorizing Material	<ul style="list-style-type: none">• Associating visual images with terms or facts you need to memorize• Repetition: rather than trying to memorize material in just a few days, set aside time over several weeks (or more) and each day practice recalling material from memory• Actively use the material you need to memorize: for instance, write out sentences, paragraphs or even stories that use terms or concepts in meaningful ways and give them context
Speaking Anxiety	<ul style="list-style-type: none">• If you're afraid you'll stumble or do badly on a class presentation, first practice out loud in front of a mirror and then practice in front of a friend or person you trust• Figure out any triggers that make your speaking anxiety worse and mentally practice avoiding these—for example, you might find it easier to speak if you can avoid ever directly looking at the instructor or can focus on just one or two people ('friendly faces') in the audience• Figure out personal strategies for feeling more relaxed and at ease: for example, having a support person in the room, or keeping a stone or object in your pocket that helps you feel more grounded• Remember to breathe, feel your feet on the ground & physically relax your muscles
Performance Anxiety/Fear of Failure	<ul style="list-style-type: none">• Tackle your anxieties head on by talking to people about them (for instance parents or instructors/mentors); holding worries inside often makes them worse• Acknowledge the impact that developing psychosis has likely had on your self-esteem, confidence, and sense of who you are as a person• Rather than holding in your fears about how psychosis has changed you, discuss them with trusted friends, mentors or clinicians• Cultivate compassion for yourself & remind yourself to pay more attention to complements than criticisms

Finally, keep in mind that being occupied and involved—with people, activities, and ideas—not only helps most people feel happier and more satisfied, but also “engages” one’s mind in new and exciting ways. For example, when someone sits down to talk with



a friend they: usually automatically ‘practice’ the give and take of casual conversation; notice, process and respond to nonverbal expressions and cues; listen to new words or different ways of expressing thoughts and feelings; and work through their own feelings and ideas through interpersonal dialogue (rather than a monologue in their heads). Similarly, a hike in the woods or a nearby nature area exposes us to (relatively unusual) sights and sounds—wildlife and animal noises, for example—as well as natural beauty, that engages us in a different way compared to walking the same route we always take to work or school. Very often, people with psychosis, including those experiencing a first episode of psychosis, become very socially isolated and less engaged in a variety of activities. Such isolation not only has negative psychological impacts, but, as these examples suggest,

cognitive impacts. Doing better (academically or otherwise) is not just a matter of spending more time studying, but also actively engaging your mind and senses in more indirect or everyday ways.

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ADMINISTRATIVE ACCOMMODATIONS

Perhaps the most well-known accommodations are those that would apply to a specific course or courses—for example, extended test time on exams for a math class. Administrative accommodations (modification to policies, practices and procedures) are also contemplated by the ADA, however, and can be an important adjunct to course-based accommodations. Please keep in mind that no accommodation is ever guaranteed; accommodations are determined on a case-by-case basis and different institutions may come to different conclusions as to whether a particular accommodation is reasonable for a particular student or not.

Area	Accommodation	How or Why It Might Help
Registration & Financial Aid	Counting a part-time course load as full time for financial aid and administrative purposes	A part-time course load would be easier to handle, but you need full-time enrollment status for financial aid or other purposes
	Early registration for courses	Helps ensure that you have access to the courses most likely to be conducive to your success (such as late morning or afternoon classes or courses with requirements that work for you)
	Changing a course to a Pass/Fail (rather than graded) after the switching deadline has passed	You experience significant unexpected challenges after the switching deadline and think you can complete the course (P/F) and do not want your GPA to be impacted
	Changing a course to a “withdrawal” or “incomplete” after the switching deadline has passed	You experience significant unexpected challenges after the switching deadline and want to be able to withdraw or take an incomplete and finish when you are doing better at a later time
	Course refund after the refund deadline has passed	Symptoms force you to withdraw from a course after the refund deadline
Academic Advising	Permission to request a specific advisor, faculty mentor or project supervisor in cases where other students cannot	Choice will allow you to work with someone who understands your unique disability-related challenges/needs and will not judge you for them
	Permission to request a particular placement (e.g., for an internship or practicum) in cases where other students cannot	Choice will allow you to intern at a site that you know will be a good fit given your disability-related needs and challenges
	Permission to require information and communications in a particular format—for instance, written communications from advisors or departmental staff	You have difficulty tracking oral communications; Oral communications may create anxiety, exacerbating voices or feelings of paranoia
	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	Accomodation	Why it might be helpful
Internships & Practica	Early registration for or preferential placement in internship or practicum of choice	Helps ensure that you have access to the internship site most likely to be conducive to your success
	Modified internship or practicum that does not alter essential features but addresses obstacles you would otherwise face completing it	Examples of modifications include increased flexibility in terms of scheduling, alternate formats (e.g., written instead of oral final presentation). Alternate testing sites, breaks.
	Additional mentoring and/or supervision assistance than would normally be provided	Due to disability-related challenges, you may need extra guidance to help you navigate these challenges; for example, working in a setting that you find triggering
Residential Services	Preferential placement in residential program/dormitory of choice	Particular symptoms or disability-related challenges (e.g., paranoia, anxiety and phobias) might be addressed through 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, or difficulty with peer relationships may make it difficult to live with a roommate
Disciplinary Processes	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 as 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 would 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 you to control your reactions
	Communications about disciplinary hearings, actions or follow-up must be provided in writing	It may be difficult for you to track oral communications or they may trigger symptoms; for example, having to communicate in person with someone who has accused you of misconduct may trigger or significantly exacerbate your voices (auditory hallucinations)

COURSE ACCOMMODATIONS

Course modifications are probably the most well-known and widely used form of academic accommodations. Accommodations are granted on a case-by-case basis and particular course accommodations are never guaranteed. Views on whether a given accommodation is reasonable can vary from campus to campus and from person to person depending on the disability. In addition, please keep in mind that this is not an exhaustive list. The accommodation process should be unique to every individual and their particular needs. These suggestions are meant to gesture toward the range and variety of possible accommodations.

Area	Accommodation	Why it might be helpful
Lectures	Assistance with note-taking	It may be difficult to hear or process what instructors are saying, and 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 helpful than the notes another student takes (not all instructors use notes that can be copied)
	Audio-recording lectures	It may be easier to follow lectures at a different time or place, or refer back to them for missing information
	Ability to freely come and go, to stand up, or engage in other activities in order to stay alert	Staying active and/or taking fresh air breaks may help with concentration and/or fatigue
	Access to preferential seating	Sitting in a particular part of the room may assist with focus; or allow you to leave without disruption, if needed
	Excused absences and flexibility regarding lectures missed due to psychiatric appointments and/or periods of heightened symptoms	Fluctuations in symptoms & associated challenges may make it critical that you have 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.

(Continued: Course Accommodations)

Area	Accommodation	Why it might be helpful
Class Discussion	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 you otherwise might. Under such circumstances, alternative ways of demonstrating engagement with course material may be extremely helpful.
Group Projects	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 elements of a course
Paired Activities	Intentionally pairing the student with another student with a strong background or skills in a situation in which pairing is otherwise random (e.g., randomly selected lab partners in a chemistry or biology course)	In many cases students are randomly paired with a partner in course or lab assignments; in some cases this might mean ending up with a partner with significant academic challenges or weaknesses; knowing that students with disabilities often face multiple other challenges, it is almost always feasible for instructors to selectively place them with a capable partner (or one who they already know to reduce stigma)
Presentations & Papers	Substituting one format for another: e.g., written presentation/paper in place of an oral presentation; or an oral presentation just in front of the instructor rather than the entire class	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 you to demonstrate content mastery in a way that does not hinge on your 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

(Continued: Course Accommodations)

Area	Accommodation	Why it might be helpful
Exams	Extended testing time	Extending testing time can help address challenges related to attention and memory and can 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 out exams may help reduce these triggers and associated symptoms
	Ability to use notes during a closed-book exam	In some cases rote memorization may be essential to a course, but in other cases it may be possible to argue that a test of memory is not needed in order to demonstrate content mastery
	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
	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 you've started an exam; under such circumstances it may be possible to request a re-take as a formal accommodation
Feedback & Communication	Regular written feedback from instructor, even when not provided to other students	Regular, written feedback can make it easier 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 or attendance can help communicate to instructors that such behaviors should be understood as disability self-management rather than irresponsibility or violations of course policy.

ACCOMMODATIONS FOR STUDENT WORKERS

Full consideration of accommodations for student workers exceeds the scope of this guide. Nevertheless, a few key points are highlighted below:

- Accommodations related to paid on-campus work are sometimes administered by the University's Human Resources (HR) department rather than the campus disability services center. In most cases, this includes students working as graduate assistants, teaching assistants or research assistants.



- Graduate research and/or teaching assistants (or fellows) may encounter additional challenges navigating accommodations related to their 'work,' including challenges distinguishing educational from work activities. Many HR departments also request that accommodations be organized around "essential functions" of the position, but such lists of essential functions are rarely provided for graduate research and/or teaching fellows. In addition, graduate positions within the same department and/or university can and typically do vary considerably in terms of roles, activities and responsibilities.

- Internships and/or practica can also present unique challenges, especially if paid (and consequently falling in between education and employment).

One should consider proactively clarifying the status of any particular internship or practicum, including what institution and office within that institution has jurisdiction over accommodations. Note that accommodations related to placement may also be administered separately from accommodations related to the actual responsibilities and activities of the position.

Because of ambiguities in the way that different types of student workers are classified, campus faculty and staff may also be less clear on how to proceed than they would be for more straightforward "student" issues related to disability. For this reason, it may be helpful to take additional steps to clarify and double-check any instructions or information that you receive with several different sources, including representatives from the Dean of Students Office.

Summary

Without a doubt, psychosis (and the social and societal reactions to psychosis) can make academic work very challenging. Postsecondary staff and faculty, including disability services staff, often do not have a very good understanding of these challenges or appropriate, helpful accommodations. Written guidance and resources are often minimal, which results in shifting more of the burden to develop appropriate accommodations onto the individual student. The goal of this guidance module is to help fill some of these gaps in terms of both academic accommodations and “self-help” strategies.

Note: Easy to print, stand-alone charts for the Administrative Accommodations and Course-Related Academic Accommodations are provided towards the end of this document.

¹ Baldwin, M. L. (2016). *Beyond schizophrenia: Living and working with a serious mental illness*. New York: Rowman & Littlefield.

Concannon, J. (2012). Mind matters: mental disability and the history and future of the Americans with Disabilities Act. *Law and Psychology Review*, 36, 89-115.

Kaminer, D. N. (2016). Mentally ill employees in the workplace: Does the ADA Amendments Act provide adequate protection?. *Health Matrix*, 26, 205-257.

Stefan, S. (2000). The Americans with Disabilities Act: A ten-year retrospective: Delusions of rights: Americans with psychiatric disabilities, employment discrimination and the Americans with Disabilities Act. *Alabama Law Review*, 52, 271-1359.

² Kranke, D., Jackson, S. E., Taylor, D. A., Anderson-Fye, E., & Floersch, J. (2013). College student disclosure of non-apparent disabilities to receive classroom accommodations. *Journal of Postsecondary Education and Disability*, 26(1), 35-51.

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.

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.



6

Troubleshooting: Campus Mental Health Legal and Policy Questions and Concerns

For many college students with psychosis and other disabilities, things work out. There might be rough patches here and there and the occasional staff member or instructor who is not especially sympathetic, but usually nothing happens that requires filing a complaint or seeking legal counsel. Unfortunately, this is not always the case, and a percentage of students do run into significant challenges, including discrimination, harassment and unwarranted disciplinary actions. The goal of this module is to walk students (and families) through some of the more common legal and policy questions and issues that the authors have run into. In addition to this information, there are several excellent (if somewhat broader) guides to student's rights on campus; these are listed in the Resources section at the end of the Toolkit. For a more in-depth review of the material in this section, see Bower and Schwartz' (2010) chapter Legal and Ethical Issues in Campus Mental Health in Mental Health Care in the College Community, Jerald Kay and Victor Schwartz, Eds. (2010).

Material in this section is organized into the following categories:

- [Definitions](#)
- [Privacy & Confidentiality](#)
- [Reasonable Accommodations](#)
- [Dismissals & Leaves of Absence](#)
- [Mandatory Assessments & Treatment](#)
- [Disciplinary Issues](#)
- [Threat Assessment Committees & Emergency Plans](#)
- [Concerns about the Future Implications of Disclosure](#)
- [Complaints & Grievances](#)



Definitions

WHAT IS DISABILITY-BASED DISCRIMINATION?

Both the Americans with Disabilities Act (ADA) and Section 504 of the Rehabilitation Act of 1973 (Section 504) prohibit discrimination against individuals with disabilities by postsecondary institutions.

In colleges and universities, the prohibition on discrimination extends not only to academic programs and coursework, but also to research activities, occupational training, housing, health insurance, counseling, financial aid, athletics, recreation, transportation, and other postsecondary aid, benefits or services (34 CFR 104.43). Other federal and state anti-discrimination laws may provide additional or more stringent protections. For example, the Fair Housing Act prohibits discrimination in a residence hall. In addition, students should consult campus-specific harassment and discrimination policies that may be more comprehensive or robust than either federal or state law.

Broadly speaking, anti-discrimination laws prohibit postsecondary institutions from denying benefits to disabled students, providing unequal benefits, enforcing criteria or administrative policies that discriminate, and taking actions that have the effect of excluding people with disabilities from programs or activities (see e.g., 34 C.F.R. §104.4). The denial of reasonable accommodations is one form of discrimination (see below). Section 504 also requires that all schools that receive federal funds designate a compliance officer and “adopt grievance procedures that incorporate appropriate due process standards and that provide for the prompt and equitable resolution of complaints” (34 CFR §104.7).

Examples of discrimination (in addition to denial of accommodations) include:

- Refusing to admit an otherwise qualified student to a graduate clinical psychology or counseling program because of a past diagnosis or history of schizophrenia;
- Steering an otherwise qualified student with psychosis away from a program or area of study in which they could succeed with accommodations and support;
- Placing a student on probation or suspension from a program in which the student is otherwise meeting the program’s academic standards for taking a medically-approved leave of absence.

What qualifies as disability-based harassment?

Isolated incidents and comments about psychosis or mental illness that are potentially offensive, but not directed towards the student, are unlikely to meet the ADA threshold for harassment. However, if offensive or stigmatizing comments (or abusive jokes, crude name-calling, threats, and bullying) are made repeatedly such that they are severe, persistent, or pervasive, and have a negative impact on the student, they create a hostile school or class environment, and may be formally considered harassment. For example, if a group of other students in a class knew that another student had been diagnosed with psychosis and repeatedly (seemingly intentionally) belittled people with psychosis—and as a result, the harassed student had difficulty doing work or attending class—there could be a hostile environment. Postsecondary institutions must respond effectively to complaints of disability harassment. When the student expresses concerns about harassment, the postsecondary institution must investigate the allegations promptly and respond appropriately. Failure to do so could be considered harassment.



What is a disability?

Under the ADA and Section 504, a disability is defined as “a physical or mental impairment that substantially limits one or more of the major life activities of [the] individual.” The definition also covers students who have a history or record of such an impairment, or who are regarded as having such an impairment. Major life activities which may be impacted by psychosis include, but are not limited to, caring for oneself, speaking, learning, sleeping, concentrating, thinking, and communicating, or the operation of a major bodily function such as neurological or brain functions. Psychotic disorders will virtually always be considered disabilities, even if symptoms are fully under control (or even absent) due to medications or other treatment or that is otherwise in remission (42 § 12102)(4)(D)).

What is a qualified person?

The ADA defines a qualified person as “an individual with a disability who, with or without reasonable modifications to rules, policies or practices . . . meets the essential eligibility requirements for . . . participation in programs or activities provided by a public entity” (42 U.S.C. § 12131(2)). In a campus setting, essential eligibility requirements must be met for college admissions; and academic and technical criteria (such as such as compliance with the student code of conduct) must be met for continued matriculation.



Privacy & Confidentiality

There are many privacy laws, I don't understand the differences.

To understand the differences, it is important to distinguish between records held by postsecondary administrative personnel, on-campus clinical treatment providers, and off-campus treatment providers. Generally speaking, FERPA (the Family Education Rights and Privacy Act) governs the disclosure of student “educational records” and information contained in educational records. Student “education records” are files, documents, and other materials that contain information directly related to a student that are maintained by a postsecondary institution.

“Under FERPA, the school's treatment records” are records that are made or maintained by a physician, psychiatrist, psychologist or other recognized professional acting in his or her professional capacity, that are made, maintained or used only in connection with treatment, and are disclosed only to individuals providing treatment. Records made by treating clinicians in the counseling center are treatment records. Treatment records are not education records. Accordingly, FERPA has only limited application to clinical personnel (including clinical staff working in a postsecondary setting).

Instead, on-campus clinicians are governed by professional licensing and professional ethics codes and relevant state laws. Off-campus clinicians and hospitals affiliated with universities are subject to stricter privacy protects under HIPAA (the Health Insurance Portability and Accountability Act) as well as professional licensing and professional ethics codes and relevant state laws. Neither “education records” nor “treatment records” are covered by HIPAA.

Transcripts, disciplinary records, and Disability Services Office records are education records. Campus records that describe or include a student's mental health status, mental health-related incidents or disability and that are created or maintained by school officials who are not treatment providers are education records and thus governed by FERPA (20 U.S.C. § 1232g(a)(4)). In addition, information gathered by campus clinicians for non-treatment-related reasons are considered educational records. For example, clinical assessments made on behalf of the school for the purposes of investigating an alleged threat rather than treatment. If treatment records are shared with non-treatment providers, the shared records are also education records. Note that treatment records from a university hospital or medical center or an off-campus treatment provider are not considered educational records and are governed by HIPAA rather than FERPA. Unlike FERPA, medical professionals and other mental health providers, are not free to disclose protected information based on observation, even if it is not directly recorded in the patient's medical record. In addition, HIPAA allows family members to be notified in the case of even a non-emergency hospitalization, if the patient agrees, fails to decline when offered the opportunity to do so, or is unable to communicate or incapacitated. FERPA and HIPAA also differ in terms of the circumstances in which private information can be disclosed, and FERPA is generally much more permissive; see below.

Under what circumstances might privacy and confidentiality protections be breached?

The standard for disclosure of information by clinical staff without consent, even in a campus setting, is when a patient threatens to inflict serious physical harm to him/herself or others and there is a reasonable probability that the patient may carry out the threat. Under such circumstances, disclosure should only occur to a person or people reasonably able to help prevent or lessen the threat, potentially including the target of the threat.

Disclosures by administrative staff, on the other hand, are governed by FERPA protections that are considerably less strong and include multiple exceptions under which confidential information can be shared without consent. **Also note that information about the student based on personal observation (or heard from third parties) is not considered part of the student's educational record and not protected by FERPA.** Thus an instructor or campus administrative officer who observes a student visibly struggling and hears reports from other students that confirm what appear to be potentially significant mental health challenges, could share this information with other staff or, potentially, with the student's parents.

FERPA exceptions permitting (but not requiring) disclosure of student educational records without consent:

- **Directory information.** Directory information includes such information as name, address, email and major that would typically be included in a student directory. When students first matriculate, they are generally given an opportunity to either opt in or out, fully or partially.
- **Legitimate Educational Interest.** School staff may disclose information contained in formal education records to other “school officials” at the same school who have a “legitimate educational interest” in the information (34 CFR § 1232g(b)(1)(A)). A school must inform students how it defines “school official” and “legitimate educational interest” in an annual notification of FERPA rights. Generally, a school official (professors, administrators, health staff) have a legitimate educational interest if that official needs to review an education record in order to fulfill his or her professional responsibilities.
- **Health or Safety Emergency.** FERPA permits disclosure without consent to appropriate persons in connection with an emergency when information is necessary to protect the health or safety of the student or other persons (Id. § 1232g(b)(1)(I); 34 C.F.R. 99.31(a)(10) and 99.36). Appropriate persons may include law enforcement, trained medical personnel and a student's parents (34 CFR § 99.36(a) (December 9, 2008)). For this exception, there must be articulable and significant threat to the health or safety of the student or others.

- **Parents of Dependents.** Postsecondary institutions may also disclose to parents of students who have been declared dependent for federal tax purposes, including adult students under guardianship, without consent (20 U.S.C. § 1232g(b)(1)(H)). The Department of Education has created several forms to help schools determine if a student is a dependent for purpose of this exception, located at <http://www.ed.gov/policy/gen/guid/fpco/ferpa/safeschools/modelform.html> or <http://www.ed.gov/policy/gen/guid/fpco/ferpa/safeschools/modelform2.html> (includes consent for independent students).
- **Another school where student intends to enroll.** Postsecondary institutions may disclose information from a student's education record to another school in which the student seeks or intends to enroll. A school must notify students (in an annual notification-of-rights) a statement that it forwards education records in such circumstances or must make a reasonable attempt to notify the student of the intended disclosure and must provide the student with a copy of the released records if requested by the student.
- **Judicial Order or Subpoena.** Records may be released without consent to comply with a judicial order or legal subpoena (Id. § 1232g(b)(1)(J)).
- **Crime & Misconduct.** For students under the age of 21, FERPA allows disclosure to parents without consent if the student has violated any laws or school policies involving possession or use of controlled substances and/or alcohol (Id. § 1232g(i). 99.31(a)(15)). Schools may also disclose the results of disciplinary proceedings related to violence and/or non-violent sex offenses to the victim or others so long as the crime has violated the school's rules or conduct policies (Id. § 1232g(b)(6)).

Note that even though a postsecondary institution can disclose information pursuant to FERPA, they must also consider whether the disclosure will violate state mental health privacy laws. State laws prohibit re-disclosure of confidential information except if consistent with the initial purpose for which disclosure was authorized. Therefore, if postsecondary administrative officers receive confidential mental health information from clinical providers in an emergency situation, they must take precautions to safeguard the information except as necessary to respond to the emergency. A postsecondary institution must comply with the state or federal law with strictest requirements.

What information might appear in an official transcript?

Transcripts cannot directly disclose either disability or any specific medical information. However, if you withdrew from courses for medical reasons, this may be noted on your transcript. In general, all withdrawals and incompletes will also be listed. If you do have a transcript that might indicate a potentially negative "pattern" of withdrawals and/or incompletes, it is often a good idea to ask at least one of the individuals providing you with a formal recommendation or serving as a reference to explicitly address these issues and head off potential concerns.



Reasonable Accommodations

What protections do the ADA and Section 504 guarantee with respect to reasonable accommodations?

Both Section 504 and the ADA *require* postsecondary institutions to provide reasonable accommodations, understood as provision of “auxiliary aids and services” (such as note-takers or written materials) and modifications to school policies, procedures or rules made to provide students with disabilities an equal opportunity to succeed in school. Accommodations and academic adjustments extend beyond coursework to financial aid, administrative policies, campus disciplinary protocols, athletics, extracurricular activities, and institutionally sponsored internships, practica and other programs.

A postsecondary institution can deny accommodations only if they can demonstrate that the requested accommodations would do the following (ADA Title III Technical Assistance Manual § III-4.3600):

- Fundamentally alter their operations;
- Alter the essential nature of the program or course of study;
- Waive essential academic and technical requirements or standards;
- Cause the institution undue financial or administrative burden.

A postsecondary institution can require students to follow its procedures to request an accommodation. Once a student has initiated the accommodations process (i.e., requested a reasonable accommodation) and provided the required documentation, the school must engage in an interactive process with the student to determine whether or not the accommodation request will be granted and/or what other alternative accommodations might be offered or substituted. Schools *cannot* deny accommodations on the grounds that a student has not met an artificial deadline such as requesting the accommodation prior to the semester.

I asked for what I think was a reasonable accommodation, but they refused it. How do I know if this constitutes discrimination or not? What do I do?

In the authors’ experience, most accommodation requests are refused on the grounds that they would constitute a fundamental alteration or waiver of an “essential” course element, standard or requirement. The courts have historically granted schools considerable deference in terms of academic decisions. This does not mean that students should not contest the denial of reasonable accommodations, however, or push schools to think more expansively and critically about what it actually means to reasonably accommodate a complicated psychiatric disability such as psychosis. For instance, schools (and faculty) may claim that rote memorization is essential to the requirements of courses in such areas as biology, chemistry, math, engineering and psychology. In reality, however, working as a scientist, engineer or psychologist generally requires very little rote memorization

and virtually none of the sort that is involved in memorizing names or facts for an exam. Arguably, then, making successful completion of core coursework dependent on memory (rather than deeper conceptual understanding), many academic fields effectively screen or keep out students with memory-impairment or deficits who might otherwise be able to succeed and pursue careers in these fields.

“Me and a lot of the people I know have just been presented with a list of accommodations that wouldn’t likely do anything to address the issues that you experience with schizophrenia. I’ve repeatedly been told a flat ‘no’ when asking for some more unusual...typically administrative stuff. They just say ‘no’ and you have to have the confidence to know that in fact they often don’t know what they’re talking about it, that you have to challenge them and say ‘hey, here’s what the ADA says, and there’s no reason why this isn’t a reasonable request. Explain to me why the ADA doesn’t apply here.’”

—Jon



If you’ve been denied an accommodation, consider the following next steps:

- **If you were told by administrative staff that a particular modification would not be allowable, even as an accommodation, but have not yet checked with disability support services, do.** Even with disability staff, you might need to remind them that significant administrative accommodations, including tuition reimbursement or refunds for classes you were forced to withdraw from due to psychosis, or changing graded courses to Pass/Fail after the deadline has passed, are not outside the scope of the ADA and Section 504 and can be justified.
- **Appeal to the disability support services office directly** and ask for a written justification of why the accommodation was denied. Ask for details regarding the identified essential academic standards and fundamental requirements, how the requested modification would change the fundamental academic standards, and any alternative ways to meet the academic standard or achieve the academic objective without lowering academic standards.

- **Ask how disability services proposes to address your limitation in an alternative way;** if the response is that your disability (psychosis) and the challenges it creates “cannot” be accommodated, start asking lots of hard questions. For instance, you might clarify if your school is in fact claiming that you are not “otherwise qualified” as a student and push them on this.
- **In some cases, faculty and/or departments may actually be willing to grant accommodations that a disability services center has refused** (the opposite can also occur); always check and if you can get what you need informally, definitely do so.
- **Contact the designated official who coordinates the postsecondary institution’s compliance with Section 504 and the ADA** – usually called the Section 504 Coordinator, ADA Coordinator, or Disability Services Coordinator.
- **File a complaint** through the postsecondary institution’s grievance procedures or file a complaint against the school with the Department of Education Office for Civil Rights (OCR) or in a court.

I am afraid that demanding or pushing for accommodations will “prove” to faculty/instructors/the school that I’m not good enough to succeed in a competitive field. I worry that I wouldn’t get strong letters of recommendation/nominated for awards/be viewed as a promising future professional. How do I navigate this?

Prejudice about psychosis and other complex psychiatric disabilities in higher education can be significant. Given the confidential nature of formal and informal recommendations, students often fear that they will be given negative recommendations because of their psychosis or serious mental illness. Given these uncertainties, consider the following:

- If specific faculty or supervisors definitely know of your history (for example, because they interacted with you during an acute episode, or you have disclosed to them for other reasons) and are otherwise people you would ask for recommendations, sit down and talk with them. Ask them directly how they feel or what their thoughts are with respect to your career prospects and history of psychosis.
- In some situations you may be safer to “come out” publicly and explicitly (and on your own terms) rather than depending on others to either disclose or keep your own history confidential (on their terms).
- Remind yourself that sometimes fears and concerns regarding potential prejudice and discrimination are unwarranted (or not borne out). For instance, a mentor or supervisor, rather than judging you for your experiences/history of psychosis may in fact become an even bigger source of support once he or she knows about your disability.

I thought about asking for accommodations that I didn't see on the list that the disability staff gave me, but does the fact that they're nowhere on this list mean that I'm unlikely to be granted them or that the instructor won't like it?

Unfortunately, many campus disability accommodation lists and suggestion sheets are much more strongly oriented to physical, sensory and learning disabilities than complex psychiatric disabilities, particularly psychosis. An extremely common complaint that we hear is that suggested accommodations do not seem useful or relevant. However, just because particular accommodations are not listed and/or are not considered "standard" by disability services staff, does not mean they aren't reasonable and in line with the mandates of the ADA. Lists of accommodations provided by Disability Services offices are not exhaustive. Under the ADA and Section 504, requests for accommodation must be individualized and considered on a case-by-case basis based on the specific needs of each student. It is true, however, that you may have to push harder and make a stronger case in order to justify accommodations that neither disability staff nor instructors are used to.

Dismissals & Leaves of Absence

Can I request voluntary medical leave or medical withdrawals?

Most schools have leave of absence policies and in the majority of situations, students can request to take voluntary medical leave or withdraw from specific courses or a program of study for medical reasons. However, some colleges require any student who goes on leave for medical reasons to obtain medical clearance in order to take a medical leave of absence. They also often place conditions on reinstatement (documentation, consultation, proof of stability, employment, classes elsewhere, treatment, personal statement) and require a detailed petition for reinstatement (see below).

Can I be suspended or asked to leave school involuntarily?

Yes. Students can be placed on involuntary leave for a variety of reasons including: (1) academic reasons; (2) safety reasons; and (3) criminal and/or student conduct violations. Criminal and/or conduct violations (discipline) are handled separately below. Examples of suspensions not uncommon among students with psychosis include:

1. Fail or seriously under-perform in required courses and fall below a program's minimum allowable GPA; (academic)
2. Say things or engage in behaviors that other students or campus staff believe to constitute a threat to campus safety. (safety)

Both types of suspensions/involuntary leaves may involve psychotic symptoms and related mental health challenges. For instance, a student may fail multiple courses, or fail to achieve adequate grades, due to unaddressed symptoms leading up to an initial break (i.e., first episode of psychosis). Members of the campus community may also conclude that a student's symptoms and/or associated behaviors constitute a threat to either the student or others. While some of these suspensions are legal, others may be due to an over-reaction to a student's symptoms. See more on threat and safety issues below.





The first time I was “suspended” I was simply told by an advisor that I could not attend classes, could not complete work associated with my fellowship and could not communicate with other faculty. Thankfully, the Dean of Students office was eventually informed, at which point they intervened and told my department that I could not be involuntarily suspended without cause. To my knowledge the faculty involved were not reprimanded in any concrete way. Some time later, I was involuntarily (“permanently”) dismissed from my program and told I could no longer enroll in classes. I was not given any reason. My GPA at the time was perfect (all A’s), I had only medically-authorized withdrawals/incompletes, no disciplinary violations and (to my knowledge) safety was not an issue and was never discussed. There was no appeals process or any option of appealing the decision. No accommodations were offered. I had a vague sense that this was illegal, but mostly thought that something must be wrong with me and that this was all my fault. I subsequently came very close to killing myself. About a year later I tried filing a complaint at the university; the officer in charge of grievances told me that there would be no point in going through with a grievance unless I wanted to be reinstated in the program (which was no longer an issue at that point as I had been admitted to a different program). The Dean of Students office essentially said the same. No action was ever taken. To this day I am unsure that anyone involved actually understood any of the relevant laws. To this day, I regret not taking stronger action and questioning the responses I received from school officials.

— Nev

I was told not to come back to school or to take an involuntary break for reasons that were not stated: how do I know if this is legitimate?

Unfortunately, the authors have heard reports of students with psychosis being told not to return to campus, threatened with arrest by campus security if they show up and/or instructed to take involuntary leave in the absence of any legitimate threat to safety or campus process. (For instance, by a faculty member, department chair or counseling staff.) If you have not been officially notified that you are involuntarily placed on leave or suspended by the university, typically by an administrative office on official letterhead, the authors suggest immediately contacting the dean of students or student affairs office in order to verify. In general, departmental faculty and staff do not have the authority to directly suspend or impose an involuntary leave. From a legal perspective, suspensions due to psychosis (i.e., in the absence of any actual safety threat, academic problems, or disciplinary violations) should not occur. If they do, consider taking action: for example, filing a complaint with the Office of Civil Rights (OCR), filing an internal grievance with the University, or seeking external legal counsel.

SUCCESSFUL LEGAL CHALLENGES INVOLVING INVOLUNTARY LEAVES

In several noted cases, students have successfully challenged the imposition of involuntary leaves of absence as discrimination under the ADA and Section 504.

► **In Doe v. Hunter College**, a student with a history of depression voluntarily admitted herself to the hospital after ingesting several Tylenol. She was medically cleared to return to school and discharged from the hospital with follow-up at an outpatient treatment provider. Nonetheless, while she was hospitalized, Hunter College changed the locks to her dorm room and evicted her from the residence hall for at least one semester. Hunter required her to receive counseling and be cleared by the school psychologist in order to return to the dorm. Doe sued, challenging the policy that required every student who was hospitalized or engaged in self-injurious thoughts or actions to take a leave of absence from the residence hall of at least one semester. The District Court found that the school had not conducted an individualized assessment of whether Doe could safely live in the residence hall. [See <http://www.kbowerlaw.com> under Cases, Order Denying Motion to Dismiss, pg. 22]. Thereafter, the case settled for a significant sum, and Hunter changed their automatic eviction policy.

► **In Nott v. GWU, No. 05-8603 (D.C. Super. Ct. 2005)**, student Jordan Nott received treatment for depression at the university's counseling center. He developed suicidal thoughts and voluntarily admitted himself to the university hospital. While in the hospital, he was informed by the residence hall director that he could not return to his dorm room until he had been cleared by the counseling center. The next day, Student Judicial Services charged him with violation of the school code of conduct for engaging in "endangering behavior." He was suspended, barred from his dorm room and campus, and threatened with arrest for trespassing if he entered campus. Rather than fight the disciplinary charges, Nott withdrew, and sued under the ADA, Section 504 and the Fair Housing Act, and other state law claims. Nott challenged the imposition of involuntary leave and the imposition of disciplinary charges for his mental health issues. GWU was widely criticized for its conduct. The case was settled and GWU thereafter adopted new involuntary mental health leave policies.

► **In a complaint filed with the Department of Justice**, a student at Quinnipiac University sought treatment for depression. She was sent to the hospital and pursuant to its mandatory medical leave policy, was informed that she could not return until she was assessed by a University designated psychiatrist. A few days later, she underwent an assessment which found that she could not return. The University denied her requests to commute from home or take classes remotely and refused to refund her tuition. DOJ found that Quinnipiac University failed to consider reasonable modifications to its mandatory medical leave policy, including allowing the student to continue attending classes either in person or remotely while living off-campus. The University entered a settlement agreement in which it agreed to change its policies, and provide tuition reimbursement and damages for emotional distress.

I have been placed on leave and told that it's because I pose a safety threat. Is this legal?

Guidance issued by the Office of Civil Rights provides that involuntary leaves be used only in rare situations in which the postsecondary institution has conducted an individualized assessment and determined that a student poses a “direct threat” to *others* and cannot remain safely at school *even with accommodations and other supports (such as intensive therapy)*.

In order to determine whether a student constitutes a “direct threat” to campus safety, school officials must undertake an individualized assessment of the student’s ability to safely participate in the college’s program, based on the most recent objective medical evidence. The assessment must consider the duration of the risk, the nature and severity of the potential harm, the probability and imminence of that harm actually taking place, and whether or not reasonable accommodations could sufficiently mitigate the alleged risks (OCR letter Marietta College, *supra.*; OCR letter to National University; OCR Complaint # 09-99-2014, 3/23/00).



“I’ve never felt as alone as I did after I got suspended from school. My parents flew me back home, and I think they thought it was because I did something wrong. I didn’t want to explain to anyone what had happened, including my friends back at school, and I seriously self-isolated.... It took me a long time to really understand that none of it was my fault and that I needed to challenge the decision. I initially had no idea what to do and my family had very few resources—no money for lawyers. With some help from a local legal advocacy group, however, I was able to proceed with things and was eventually reinstated. I’m grateful that I didn’t just give up—came very close.”
—‘Jackson’

Before placing a student on leave, schools must also consider less restrictive alternatives. Examples include:

- Leave from housing but not from school;
- Living with a parent or family member (on or off campus);
- Attending intensive counseling or therapy sessions.

If you have been asked to go on leave without any discussion of alternatives, demand them. Note that treatment recommendations (such as daily check-ins with counseling staff) should be developed collaboratively between the student and his/her clinicians, not imposed by campus administration.

The law regarding imposition of leaves of absence when a student poses a safety risk to him or herself is more unsettled; however, recent OCR decisions provide some guidance. In cases involving threat to self, postsecondary institutions relying on generally applicable policies addressing student safety and health must treat students with disabilities the same as similarly-situated students without disabilities. In addition, they must conduct individualized risk assessments and ensure that their actions are not based on fear, stereotypes or prejudice against students with disabilities. Finally, they must consider whether reasonable modifications would permit the student to continue to participate in the postsecondary education program.

OCR rulings have also clarified that schools must provide *due process* before students are required to go on leave (OCR letter to Marietta College, *supra*; OCR letter to Guilford College, Complaint # M-02-2003, 3/6/03). Due process protections include:

- Advance written notification that the school is considering placing the student on involuntary leave;
- Opportunity to respond and submit evidence in support of remaining at school;
- A formal hearing;
- Opportunity to appeal the school's final decision.

Students should note that the above guidance applies whether or not the student is an undergraduate, graduate or professional student (e.g., law or medicine).

Can the university make reinstatement conditional, whether or not initial leave was voluntary?

Within limits, schools can impose some conditional requirements for reinstatement following either voluntary or involuntary leaves of absence. However, as is the case for initial decisions to impose involuntary leave, whether conditions are imposed and the type of conditions imposed must be individualized and related to the reason for the leave of absence.

Schools typically require students to submit a reinstatement petition or application in order to initiate the return process, and often require:

- Medical clearance;
- Documentation of steps the student has taken to reduce risks to an acceptable level;
- Limited access to medical/psychiatric records for a specific purpose (not open-ended access).

Students must be provided with clear guidance on what constitutes sufficient medical documentation. Throughout this process, schools cannot require that the student's disability be 'cured' or that behaviors stemming from the disability be eliminated or absent (unless they represent a direct threat). Students must also be allowed to appeal an initial decision to deny reinstatement as well as the specific conditions of return.

I've been forced to go on leave, and while on leave told that I cannot come on campus, and cannot contact either students or faculty. Can my school do this?

Postsecondary institutions regularly require that students on leave remain away from campus and residence halls. Such broad restrictions on students that take medical leave may be legally suspect. In extreme cases—primarily where the student represents a serious risk to campus safety—where individually indicated, schools may be able to prohibit the student from contacting campus staff, coming on campus or attending campus events. If such serious risks are not present (for instance a student who experienced a severe psychotic episode but did not engage in any concerning behaviors and quickly bounced back after an extended hospitalization and/or medication adjustment is planning to apply for reinstatement starting at the beginning of the next semester), limitations on the student's communications or campus participation which isolate the student from friends and campus supports should not be imposed.

Mandatory Assessments & Treatment

I've been told that I need to undergo a medical assessment to determine whether or not I truly pose a threat. What should I do?

Schools are free to request a medical assessment to determine threat, and it is almost always in your best interest to comply. In most cases, refusal would serve as grounds for immediate suspension. If your school has requested that you provide a psychiatric assessment, however, you should be free to use your own (external) mental health provider. Ideally this would be a clinician who knows you well, and is not an employee of your school (or the school's affiliated medical center/school of medicine). If you have only recently moved or started school, you may be able to use a clinician from your hometown who is more familiar with your history and circumstances. A clinician who does not know you is much more likely to err on the side of caution in confirming risk/threat than a clinician who has worked with you for a long time and with whom you have established a strong, mutually trusting relationship. Clinicians without substantial experiencing treating and working with psychosis are also much more likely to judge psychotic symptoms as risky or potentially threatening.

In retrospect I feel like I was kinda naïve, because I decided to see a therapist at the campus counseling center, and then she was the one who actually confirmed that yes, I was a threat. I told her the exact same sort of things I told my therapist back at home who understood that yeah, voices say these sorts of things—the voices, not me. You would hope that anyone with a PhD would understand psychosis, but the reality is that they clearly don't."

—'Alex'

In risk-related assessments, campus-based staff (including campus counselors, student health providers, and clinicians associated with a campus-based medical center or school of medicine) may owe their primary loyalty to the school (including protecting the school against potential legal liability) rather than the student. They may also be conflicted in more indirect ways due to their own role creating or developing campus policies such as behavioral health threat and/or emergency protocols, and mental health related leave.

I've been told that a condition of returning to campus is that I follow such an intensive treatment program that it would make it difficult or impossible for me to remain a full-time student, taking the classes I need to graduate. Can I refuse?

If a student's treatment provider has opined that the student requires a certain level of treatment in order to safely remain on campus, a post-secondary institution can require the student to comply with the treatment plan. The student can request accommodations, such as waiver of time to degree requirements, if necessary to allow them to participate in the academic program.



Disciplinary Issues

I feel like I've been disciplined for (or because of) my symptoms. But I also feel really confused about the distinction between behaviors associated with my psychosis and "misconduct"...

The ADA requires that disciplinary rules must be non-discriminatory, and applied in a non-discriminatory manner. Disciplinary rules may not be imposed based on prejudice or inaccurate stereotypes. Postsecondary institutions can impose disciplinary action for conduct violations, even if the conduct is a symptom of the student's disability. For example, a school can expel a student for brandishing a gun in class, even though the conduct occurred in the midst of an acute psychotic episode, as long as a student without a disability would be expelled for the same offense. A postsecondary institution is not required to give the student a 'second chance' because the conduct is disability-related. Examples of behaviors directly attributable to psychosis which can violate student conduct codes include:

- Physical or verbal altercations with a member of the campus community that the student, due to paranoia or persecutory delusions, believes is stalking or monitoring him/her;
- Petty theft, trespassing or public nudity motivated by symptoms (voices/delusions);
- Cheating or plagiarism (or acts presumed to fall under these categories) in fact stemming from delusions (for example, that the student *is* the famous writer or scientist whose work he/she puts forward).

However, as a reasonable accommodation, schools should consider the student's disability as a mitigating factor in determining whether to impose a penalty and what sanction to impose. This is especially compelling when, as a result of treatment or other interventions, the student can demonstrate that he or she is likely to comply with the code of conduct in the future. See OCR letter to San Diego Community College (Complaint # 09-98-2154, 12/30/99) (involving a situation in which the student is alleged to be disruptive or a source of discomfort for classmates or other members of the campus community).

What protections do I have during disciplinary hearings?

As is true for other campus activities and processes, you have the right to request disability-based accommodations during a disciplinary hearing. Such accommodations might include the presence of family, clinicians or advocates who you consider to be supporters (who might otherwise not be allowed), written (rather than oral) documentation

of findings, written justifications for any actions taken, and permission to audio-record meetings or hearings. You also have the right to request that your disability be considered a mitigating factor in the imposition of any sanctions.

Some postsecondary institutions provide an alternative forum to hear situations where a disability is directly related to the disciplinary infraction. The alternative forum may include campus staff with expertise in disability issues and, to protect student privacy, may exclude other students who would otherwise be present as members of the school's conduct board. If an alternative forum is available, the student should be able to elect whether to proceed in the alternate forum. [OCR letter to Woodbury University (Complaint # 09-00-2079, 6/29/01).]

Even in a best case scenario, involvement in a disciplinary process can be distressing and emotionally overwhelming, potentially further triggering or exacerbating the symptoms that led to the disciplinary infraction in the first place. If you feel overwhelmed or unable to cope with the process, you might want to consider taking a voluntary leave for mental health reasons, and request that the school halt disciplinary proceedings while you are on leave. However, you always want to consider the school's readmission or reinstatement policies and challenges that taking a leave might create down the road.





Threat Assessment Committees & Response Plans

What do I need to know about campus emergency plans?

As mentioned elsewhere in the Toolkit, in the wake of high profile school shootings over the last 15 years, most schools have developed campus emergency plans that include threat assessment teams or committees. Some schools have opted to separate out general threat or emergency teams (encompassing natural disasters as well as campus violence) and behavioral health teams that explicitly focus on concerns related to mental health. Separating these functions is considered a best practice and helps reinforce the separation between violence and mental health; however, many campuses continue to combine these functions. The Department of Education has directly encouraged schools to implement such committees [“The Department encourages schools to implement a threat assessment program, including the establishment of a threat assessment team that utilizes the expertise of representatives from law enforcement agencies in the community” (Federal Register / Vol. 73, No. 237 / Tuesday, December 9, 2008 / Rules and Regulations at 74839).]

At many schools, descriptions of emergency protocols for threat assessment teams and/or behavioral intervention teams are publicly posted. Emergency plans for threat assessment typically include:

- Protocols and procedures for handling a student (or other member of the campus community) perceived to be an immediate threat;
- Guidance on available referral pathways within the university;
- The composition of the administrative or advisory team charged with overseeing emergency planning and implementation and/or conducting threat assessments.

Understanding your campus’ specific behavioral intervention or threat assessment policies and procedures can help you plan appropriately and reduce distress and anxiety if you end up being reported or assessed as part of either of these teams.



Concerns About the Future Implications of Disclosure

I'm a medical, clinical or law student, is it true that if a history of psychosis is documented I could be ineligible for required internships, licensure or the Bar?

We are frequently approached by graduate students with serious concerns about the implications of disclosing or documenting a diagnosis of psychosis for professional licensure. Laws governing what information licensing boards and formal clinical or medical internship or residency sites can require in the way of medical and/or psychological history can vary considerably both by State and by program, making these questions difficult to navigate outside of specific settings and situations. A further challenge is the potential that programs will informally discriminate during the admissions or matching process based on a history of psychosis or schizophrenia. Generally speaking, since broad questions about mental health history rely on mere speculation, stereotypes, or generalizations about people with disabilities and do not predict fitness, they are prohibited by the ADA. Rather, questions about a student's prior behavior is the best predictor of future success. Questions about mental health would only be appropriate if an applicant raises his or her mental health condition in response to questions concerning past conduct. As this is a developing area of law, the authors strongly recommend investigating both formal and informal practices within your field, institution and state.

For example, the Department of Justice recently found that admitting law student applicants with disabilities to the Vermont and Louisiana bars on a "conditional" basis due to their mental health diagnosis and history of mental health treatment screens out applicants with disabilities in violation of the ADA. Questions such as 'whether an applicant has been diagnosed with or treated for bipolar disorder, schizophrenia, paranoia, or any other psychotic disorder in the past five years' are unnecessary, overbroad, and burdensome for applicants. The DOJ urges the use of conduct related questions to assess an applicant's fitness to practice law rather than questions about an applicant's mental health diagnosis or treatment. DOJ's guidance will, no doubt, reverberate in other states. For example, in June 2016, the Washington State Supreme Court removed questions about bar applicants' mental health history from character and fitness evaluations.

I've heard that the Peace Corps will not accept volunteers with a documented history of schizophrenia or other psychotic disorders. Is this true? How is this legal?

Unfortunately, the Peace Corps (and likely other programs) do utilize medical exclusion criteria, including a diagnosis of schizophrenia or bipolar I. The rationale behind these exclusions is that, should an emergency arise, it might not be possible for program administration to link the volunteer with adequate medical or psychiatric supports and services. It is possible, however, that at some point in the future, programs such as Peace Corps will nevertheless face lawsuits by persons with a history of psychosis who have fully recovered and/or are in full remission.



Complaints & Grievances

What do I do if I feel like my rights have been violated?

While internal grievance procedures vary from school to school, Section 504 requires postsecondary institutions to have a 504 compliance office (or 504 liaison). Postsecondary institutions that accept federal funds must also have clear internal grievance procedures and mechanisms. In addition, federal entities operate independent grievance and investigative branches (see table below). Students and families can also seek private legal counsel or legal advocacy services provided by federally mandated Protection & Advocacy (P & A) agencies (see sidebar).

Nature or Setting of Violation	Responsible Entity
Denial of academic accommodations, disability-based discrimination or harassment experienced as a student	US Department of Education, Office for Civil Rights (DoE OCR) Or DOJ, state human rights departments, accreditation boards, boards of trustees.
Denial of work-related accommodation (e.g., as a graduate fellow); disability-based discrimination or harassment experienced as a student worker	US Equal Employment Opportunity Commission (EEOC) ; or state human rights commissions
Violation of medical privacy rights associated with the Health Information Privacy & Act (HIPAA); for example, unallowable disclosure of health information without student's consent	US Department of Health & Human Services, Office for Civil Rights (HHS OCR)
Violation of educational privacy rights associated with the Family Educational Reporting Act (FERPA); for example, unallowable disclosure of educational information without student's consent	US Department of Education, Family Policy Compliance Office (DoE FPCO)

Should I file a grievance at my school or with a federal agency? What's the difference? Is filing a grievance the same as a lawsuit?

Postsecondary institutions have to comply with state and federal laws. Federal investigations are governed entirely by federal law. Institutional investigations are governed by school-based policies and procedures and any relevant state laws. In some places, institutional and/or state-level protections may actually be more robust than those found in federal law. You can also simultaneously file both an internal complaint and a federal complaint; if you do so, the federal investigation may not commence until the internal investigation has finished and rely largely on internal findings. Filing a grievance or complaint is not a lawsuit. If you decide to sue your school for discrimination or harassment, you can do so whether or not you filed a separate grievance, and can sue even if your grievance or complaint was determined to be “unsubstantiated.”

“I filed a lengthy complaint, naming multiple faculty members in my program; over 6 months later the investigator wrapped everything up and sent me a handful of emails saying that none of my allegations could be substantiated. They said I had the option to appeal, but I just didn’t have the energy for that.

I subsequently graduated, but a year later other students in the program emailed me to let me know of all the changes that had taken place in the year following the investigation: a new disability policy had been developed and implemented in the department, and all the faculty were now required to go through disability and mental health sensitivity trainings. I felt like, “well okay, after all it really had an impact.” It was worth it.

—‘Jade’



What happens after filing an institutional grievance or complaint?

For institutional grievances, a designated officer or investigator will typically kick off the process by meeting with the student individually to hear more about his or her experiences. The officer will then decide whether or not to pursue an investigation; decisions not to investigate can be appealed by the student. If the officer decides to proceed, the student will typically be brought back in for one or more lengthy question and answer sessions, and asked to submit written testimony and/or any available documentation (such as relevant emails). Once the investigation is formally opened, the student is generally allowed to request that the staff or faculty against whom charges have been made not be involved in supervising, administratively overseeing, or grading him or her for the duration of the investigation. Depending on the nature of the charges, campus legal counsel may also be notified. Students should note that that institutional legal counsel act to protect the interests of the college or university (including faculty and staff), not the student. Investigators will generally meet with all relevant persons the student names (either as witnesses or perpetrators) and request any documentation or supporting materials relevant to the student’s allegations. Investigators may also obtain direct access to campus emails, and student’s educational and/or health records (as applicable). The length of the investigatory process can vary tremendously, ranging from several weeks to many months. If the investigator finds that the school or school staff have violated the student’s rights, they will inform the student of this and pursue a plan for specific corrective action. If they cannot substantiate the allegations they will inform the student in writing, typically with little to no elaboration or additional detail.

If investigators report that they could not substantiate my allegations does that mean all my efforts were wasted?

No. A formal investigation sends a very strong message that discrimination and/or violations of student's rights stemming from a diagnosis or experiences of psychosis are illegal and unacceptable. They can also serve as a more general "refresher" on rights and protections related to disability and associated laws such as the ADA. While these impacts may not benefit you personally, their impact on future students with psychiatric disabilities, including psychosis, may be considerable.

How do I know if I might need a lawyer?

If you feel that your rights have been violated consider obtaining private or free or low cost legal assistance. The advantages of retaining legal counsel can be considerable. A one-time consultation can provide valuable advice and enable you to effectively advocate for yourself. Often legal matters discussed in this Toolkit can be addressed through limited representation. For instance, we have seen schools swiftly comply with a student's requests as soon as they are informed that legal counsel has been retained or once they receive a direct communication from the student's attorney. Unfortunately, locating an attorney with the qualifications and experience you need is not necessarily easy.

Protection & Advocacy (P & A) Services?

P & A's are federally mandated free legal services provided to people with disabilities. P & A services are available in every state. The National Disability Rights Network (NDRN) is the voluntary national association of P & A services. Students with psychosis may fall under the jurisdiction of Protection and Advocacy for Individuals with Mental Illness (PAIMI) P & A services. At the federal level, the Substance Use and Mental Health Administration (SAMHSA) oversees the PAIMI P & A program. Each state PAIMI program sets internal priorities each year; some work with students experiencing discrimination in higher education. NDRN maintains a comprehensive list of P & As by State:

www.ndrn.org/en/ndrn-member-agencies.html



7

“I Just Got a Letter...”: What to Do If You’ve Just Been Suspended or Asked to Involuntarily Withdraw from School

Formal letters communicating disciplinary actions, hearings, suspensions, dismissals and/or involuntary leaves of absence are often received in the midst of an existing crisis, typically with limited timeframes for responses and/or appeals. The goal of this information brief is to provide quick, practical guidance to students and family members faced with time-sensitive decisions about how to respond and what to do.

BREATHE AND BE KIND TO YOURSELF

Disciplinary letters and/or suspensions often come as a shock to both students and their families. You might be unaware that you did anything wrong, for example. Or you might find yourself unexpectedly hospitalized, only to be presented with a formal letter or statement of action before you’ve even been cleared for discharge. As in other tough situations:

- Breathe and give yourself a little time to process before reacting or responding;
- Do not blame yourself. Dealing with significant mental health challenges is extremely difficult, and those challenges can be compounded by stigma and social rejection. You’re not alone, and whatever the letter you received says, remind yourself that you’ll get through it.

“I was feeling incredibly depressed and ended up in the hospital... I thought, ‘okay, this is not the end of the world, I’ll be able to go back and finish my classes’ but then they told me no, that I couldn’t go back to my dorm and needed to take a leave of absence. I was speechless. And then I really wanted to end everything. And then I just sunk back into a really dark place... It took time, and I eventually went back and finished school somewhere else, but there needs to be more support for students. You suddenly feel like you’re so alone, and you’re not, but how do you know that?....”



THINGS TO DO AND ASK FOR RIGHT AWAY

- If you’re given a very short deadline for a response or appeal, ask for more time, both as an accommodation and to seek legal advice.
- Even if you don’t have the resources to seek private legal counsel, you can still tell university staff that you want time to meet with (or retain) a lawyer. There may be free or low costs attorneys or organizations that can provide advice and assistance. Sometimes just a hint of legal action will prompt staff to slow down, reconsider or soften their tone or demands.
- If you work with a clinician you trust, it may be helpful to speak with him or her about what is happening. If school administrators or campus-based clinicians are claiming that you are a threat (or that it would not be safe for you to return to campus), and your treatment provider disagrees, it may be helpful for him or her to contact the school directly. External providers may be in a position to effectively counter or soften administrators’ or campus-based clinicians’ concerns.
- While you or family members may feel hurt and angry, try to stay cool when communicating with campus staff; expressions of anger are unlikely to play out in your favor and can undermine your claims and case.

- Record (with consent) or take **meticulous notes on any oral exchanges or conversations:**
 - **Send follow-up emails after oral conversations in which you summarize what you heard** and ask others present to clarify or respond within a certain timeframe. These emails can later be used as documentation if you file a complaint or lawsuit.
- **If the postsecondary institution is placing you on involuntary leave, request that they waive their involuntary leave policy and provide accommodations.** The accommodations you request can also serve to provide assurances to the institution representatives which address their concerns. For example, if they express concerns with the stress of remaining on campus, ask to reduce your course load, withdraw from extracurricular activities, and get extended deadlines or incompletes.
- **If they are considering placing you on an involuntary leave because of safety concerns related to being alone in the dorm, ask to have a parent stay with you for a brief period of time or ask to stay off-campus with a parent or other caregiver.** If you are not allowed to remain in the residence hall, ask if you can continue to attend classes.
 - **If you cannot attend classes in person, ask to continue with your classes remotely,** for example, by recording classes and lectures, by obtaining class notes and assignments, and by turning in assignments electronically and taking exams remotely.
 - **Ask to continue with your coursework during any appeal period.**
 - **Propose less drastic alternatives which will allow you to salvage the semester** while providing the postsecondary institution with assurances that you are not a safety risk.
 - **Ask for any opportunity to provide evidence that you do not pose a safety concern to yourself or anyone else.**
 - If you are placed on a leave of absence, **ask for a tuition reimbursement.**
 - **Ask that any conditions placed on your leave be individualized,** including the length of leave (to be determined by your treatment provider), and requirements during the leave.
- If you have not already done so, **register with the disability services office and ask for assistance.**
 - If you are not allowed on campus, ask for permission to come on campus to meet with disability services staff, or ask to speak with them by telephone.

IF THE ACTION IS DISCIPLINARY

- If you're called in to a disciplinary meeting, **ask for more time**, to process the information and to request guidance. Request that friends, family members, an ally or legal counsel be allowed to attend.
- If your actions or behaviors are directly related to a psychiatric disability, **communicate that you have a disability and that you feel the conduct is disability-related**.
- As a precautionary step, **you may want to obtain additional documentation from your psychiatrist or therapist**, explaining the nature of the relationship between your behavior(s)/action(s) and disability.
- Request that your disability be considered as a mitigating factor.
- If you have not already done so, **register with the disability service office**.

“Getting placed on involuntary leave was one of the most difficult, damaging things that has ever happened to me. I feel like I lost so much...felt so devalued. It took me a long time to come full circle as an advocate, but now I realize how many people have experienced similar things. I know it wasn't me, wasn't my fault, and isn't theirs. Together, we all need to work for change. People with psychosis are not mass shooters and serial killers: we're real people, with hearts and a tremendous contribution to make if given a chance. “

Summary

Stay calm and collected and, above all, do not blame yourself. Know that you're not alone and that the only way policies and systems will change—for you and for others—is by challenging prejudice and discrimination, and by advocating for yourself and, by extension, others who may come after you and face similar circumstances. Transform the anger, frustration, sadness and hurt you feel into action and, eventually, change.



8

Navigating Multiple Taboos: Early Psychosis & Grad School

Graduate students are often faced with particularly difficult challenges when it comes to the intersection of psychosis, treatment, disclosure and academic accommodations. This is perhaps especially true in competitive, high-pressure programs and fields in which students may feel like any “sign of weakness” could become a nail in their professional coffin.

FIRST...IT CAN BE DONE

While navigating graduate school with psychosis can certainly be challenging, we do not want to send the message that it can't be done. See the Back To School Toolkit's Voices of Success brief for an overview of the accounts of dozens of current and former graduate students with psychosis, including (now) successful researchers, scientists, university faculty, clinical psychologists, and physicians.

“If you have psychosis, you have a ‘disability’ that directly affects the very thing that graduate school is all about: the brain and mind. Proving to yourself, and proving to others, that you can excel academically and intellectually, in spite of psychosis, can be monumentally difficult. And accommodations spring up right in the middle of these challenges: how can you simultaneously send the message to faculty that you’re smart and full of potential and at the same time ask for extra help with intellectual work? I don’t know how to resolve this. I’ve mostly just tried to get through things on my own, and not let professors know what I’m really struggling with.”

UNIQUE CHALLENGES

Compared to undergraduates, graduate students face a number of unique challenges including additional complications with respect to both accommodations and disclosure. For example, accommodations for the “work” component of graduate fellowships may be routed through an institution’s human resources office, while “educational” accommodations are processed by the student disability services office. Staff providing accommodations (as well as student clinicians) may have no experience assisting graduate or doctoral students, and may struggle to recommend useful modifications or supports. The stakes of disclosing can feel overwhelming, given tremendous stigma, and uncertainty around what a label of “psychosis” or schizophrenia might mean for a student’s academic and professional future. This is especially so if graduate students work with clients or patients.

THE IMPORTANCE OF MENTORS & ADVOCATES

A common theme that runs through conversations and research projects focused on the experiences of graduate students with psychosis and other significant psychiatric disabilities is the importance of academic and professional mentors, or other “champions” within your department or field. Trying to bear all the challenges of psychosis alone, without telling anyone, can take an enormous toll. A senior ally, who both understands your unique challenges and is strongly invested in your success, can be invaluable. Finding such a person may, of course, be more or less difficult depending on your program or field. If you feel like you haven’t been able to find someone locally, we strongly suggest reaching out to external faculty and/or other potential mentors.

“The two things that helped me the most were mentors who cared, who stuck with me, who wanted to see me succeed, and finding graduate students with similar experiences. Even with wonderful clinical supports, for so long I felt so, so alone. I would hear other clinical grad students talking about “clients with schizophrenia” in a demeaning way and this sense of rage would just well up in me.... But I just kept it all in, and sometimes even felt guilty for feeling so angry...but then I met other people like me, with the same anger, and the same struggles, and collectively I feel like we turned that into something positive: empathy, solidarity, common cause.”

CONNECT WITH OTHER GRADUATE STUDENTS

Given all the challenges you likely face, connecting with other graduate students with psychosis or other significant psychiatric disabilities, particularly those in the same field as you, can be a critical source of information and guidance as well as psychological support. In many cases, the biggest barrier to such networking is the invisibility of graduate students with disabilities and difficulty locating other people like you. Given the array of social media services and sites now available, including dedicated “meetup” platforms, it might only take an anonymous post or query and others will begin to emerge from the woodwork.

YOUR OWN WORST ENEMY

Graduate students are, in general, particularly prone to imposter syndromes: ‘I don’t belong here;’ ‘people think I’m smart and really I’m not;’ ‘it’s just a matter of time before I fail or they see me for what I really am.’ The additional layer(s) of psychosis generally don’t help. Worst of all, you might begin to feel so hopeless about your future, or so incapable, that you drop out or give up on your hopes or dreams. If you’ve already crossed a certain threshold of demoralization and low self-esteem, things are not going to change overnight.

But There Is hope..... You Are The Future

Social and institutional change often happens when members of an under-represented and marginalized group are able to move into positions of power and influence. As the graduate students of today assume leadership positions in policy, medicine, social services, research, academia, business, technology and the arts, they (you!) will find yourself in a position to challenge prejudice, counter damaging stereotypes, and mentor and inspire the next generation of students.



9

Early Psychosis & Violence on Campus: Just the Facts

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.¹ 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.²
- 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.³
- **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.**⁴



“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.”

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.** ⁵

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.⁶

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.**⁷
- The internalization of social stigma is strongly linked to suicide risk and poor outcomes among individuals with psychosis;⁸ **college students with mental illness consistently describe stigma as one of the most significant barriers to their success and well-being on campus.**⁹

Additional Readings

Boydell, K. M., Stasiulis, E., Volpe, T., & Gladstone, B. (2010). A descriptive review of qualitative studies in first episode psychosis. *Early Intervention in Psychiatry*, 4(1), 7-24.

Fox, J. A., & Fridel, E. E. (2016). The tenuous connections involving mass shootings, mental illness, and gun laws. *Violence and Gender*, 3(1), 14-19.

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.

Mowbray, C. T., Megivern, D., Mandiberg, J. M., Strauss, S., Stein, C. H., Collins, K., ... & Lett, R. (2006). Campus mental health services: Recommendations for change. *American Journal of Orthopsychiatry*, 76(2), 226.

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.

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.

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

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

³ 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.

⁴ 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.

⁵ 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.

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

⁷ 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.

⁸ 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.

⁹ 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.

¹⁰ 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.

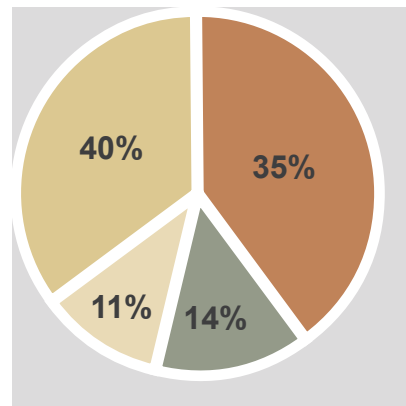
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Voices of Success: The Work & School Stories Project

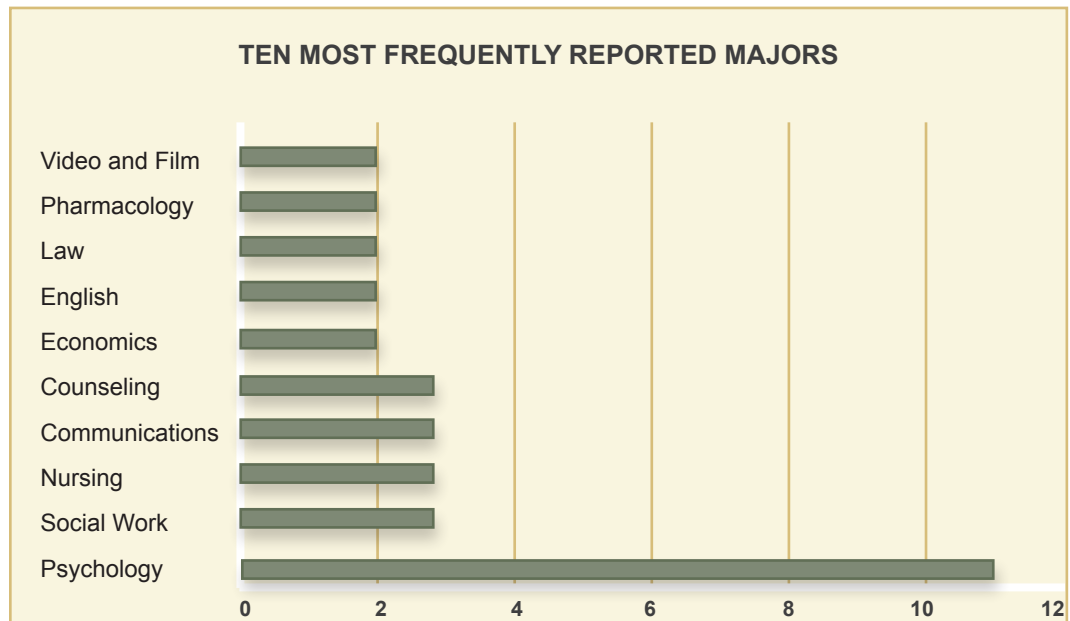
Unfortunately, successful adults with a history and diagnosis of psychosis are largely invisible in society due primarily to stigma and the risks of speaking out. This invisibility can send young people (and their family and academic mentors) the message that success across an array of fields and disciplines is unlikely. The [Work & School Stories Project](http://www.voicesoutside.org) (www.voicesoutside.org) 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

- High School
- BA
- MA
- JD/MD/PhD



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."

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.

Hinshaw, S. P. (2008). *Breaking the silence: Mental health professionals disclose their personal and family experiences of mental illness*. Oxford: Oxford University Press.

Jamison, K. R. (2015). *An unquiet mind: A memoir of moods and madness*. New York: Picador.

Longden, E. (2013). The voices in my head. *TED Talk Accessed at* http://www.ted.com/talks/eleanor_longden_the_voices_in_my_head

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/>

North, C. S. (1989). *Welcome, silence: My triumph over schizophrenia*. New York: Avon Books.

Saks, E. R. (2008). *The center cannot hold: My journey through madness*. New York: Hyperion.

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 Virtual Resource Center.](#) National Association of State Mental Health Program Directors (NASMHPD).

[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 than 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.”

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Administrative Accommodations for Students with Psychosis

Area	Accommodation	Why it might be helpful
Registration and Financial Aid	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
Academic Advising	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	Accomodation	Why it might be helpful
Internships & Practica	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 than 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
Residential Services	Preferential placement in residential program/dormitory of choice	Particular symptoms or disability-related challenges (include 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
Disciplinary Processes	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

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Course-Related Academic Accommodations for Students with Psychosis

Area	Accommodation	Why it might be helpful
Lectures	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
Class Discussion	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
Group Projects	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
Paired Activities	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
Presentations & Papers	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
Exams	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
Exams	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
Feedback & Communication	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