



BEYOND HIGH SCHOOL

*Self-advocacy is key for young adults on the spectrum
to succeed at the college level . . .*

BY HANNAH ENENBACH

Making the transition from high school to college is often dramatic—and in some cases, traumatic—for graduating students. Suddenly, they are expected to motivate themselves to attend class, study on their own time, and pace themselves in preparation for longer-term assignments or cumulative exams. For students on the autism

spectrum who require disability accommodations from their new colleges or universities, the difficulties multiply.

The shift of the responsibility of initiative from the parent and school to the student is one of the most challenging aspects of moving into the world of higher learning. This shift is an even bigger adjustment

than most take it to be, requiring not only a good handle on a handful of executive functioning skills, but also strong motivation and the ability to self-advocate. Comprehensive transitional supports when starting postsecondary education are essential in increasing the probability of being successful.

RESEARCH THE OPTIONS

Colleges vary in the amount of support they provide to what they call “disabled students”. (Controversy rightly exists among advocacy groups about whether autism should be categorized as a disability; here, I use the term only because colleges count students with autism spectrum disorders in the category of those they

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serve under the umbrella of Disability Services.) Some have well-established, comprehensive Disability Services that do a great job with making themselves visible right from the very beginning. They may maintain a strong presence at new student orientations, thereby putting themselves right in the line of sight of students who may need them. Once students self-identify, they may be provided with a personalized counselor who assesses their needs, follows up with task lists for them, communicates with their professors on their behalf with their consent, provides them with extra tutoring, and walks them through the use of every resource on campus that could benefit them.

The above is a best-case scenario, however. Unfortunately, due to lack of resources, funding, or training, there are many other institutions that don't have the funding, the resources, or the training to maintain a comprehensive approach like this. While by law a college or university must offer resources to ensure equal access to its programs and buildings, the specifics of the law mainly refer to what the school must be willing to provide, not how convenient its services have to be.

In some cases, students may not have a dedicated counselor. Reminders may come only as form letters sent to all students, or not at all. Professors may not be aware of the processes of Disability Services due to a lack of communication between the office and the rest of the school. Alternative test-taking locations may be overcrowded, requiring students to wait in line or schedule exams at inconvenient times. Certain accommodations may be inconvenient or laborious to receive; for example, only one staff member may be available to serve as a scribe or convert text into audio for many students.

THE SELF-IDENTIFICATION PROCESS

Researching a school's Disability Services center should be a crucial part of the college search for any

student with autism. But even in the best of cases, the student still must take the first step of self-identification. This is a difficult thing for a

student who has always had someone come to them.

The experience is jarring, a sudden thrust into the ownership of

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CRITICAL STEPS IN OBTAINING DISABILITY ACCOMMODATIONS

In addition to requesting and using disability accommodations in a postsecondary setting, students must also develop the skills and knowledge they are required to have and demonstrate throughout their time in college and university settings. Here is a chronological list of the critical steps students need to take:

- 1 **FIND THE CENTER AND ATTEND ORIENTATION**—Most postsecondary institutions require potential students to attend an orientation that familiarizes students with the way the Disability Services Center works and instructs them in how to become a client. These orientations take at least a few hours and only take place at preselected times. During these orientations, lots of information is presented quickly and lots of materials are given to the student. This requires organization, time management, working memory, task initiation, communication and response inhibition.
- 2 **ACCESS AND OBTAIN DOCUMENTATION OF DISABILITY**—In a postsecondary setting, students will need to provide the Disability Services center with documentation of their disability. The documentation must include a clearly stated and supported diagnosis, current information with relevant history, a description of the functional limitations, a justification for recommended accommodations, and the professional credentials of the evaluator. Sometimes, IEPs are not enough. This means that the student must either locate recent documentation that already exists or find a credentialed evaluator (ideally one with whom they have worked before), make an appointment, receive the results, and bring them to the office. This requires organization, task initiation, and goal-directed persistence.
- 3 **REQUEST ACCOMMODATIONS**—An important thing to note is that in a university setting, students with the same disability will not necessarily receive the same accommodations. Disability Services will assess the impact of the disability rather than the label. Therefore, it is not enough for a student to simply walk in with a documented diagnostic label and expect the center to do the work of figuring out what accommodations are needed. Students will need to work with their professors and counselors in order to assess how their particular differences will manifest in a classroom, homework, or test-taking environment. This requires self-perception and awareness, task initiation, communication, and flexibility.
- 4 **FOLLOW UP ON APPROVAL FOR ACCOMMODATIONS**—Receiving approval for accommodations is only the first step towards utilizing them. What comes after an approval letter can often be a confusing maze of disclosure, where the student must figure out who will let the professor know of the accommodations, who is responsible for scheduling exams outside the classroom, who is responsible for making sure there is a note-taker, who scans the text into audiobook or e-book form and where that person is located, etc. Students must schedule time outside their school schedule to take care of these things. They must make their own appointments with counselors, visit their professors before or after class or during office hours, and keep tabs on all the deadlines that they must stick to in order to make sure their accommodations are ready for them when they need them to be.

one’s own success. That, coupled with executive functioning mastery and comfort with self-advocacy, is something most students with autism simply cannot be expected to possess straight out of high school. While it would be wonderful if they did, the reality is that even consistent preparation in an environment where parents and teachers hold the reins cannot usually adequately prepare the student for a sudden transition into an environment where they are wholly responsible for themselves.

I am the academic coordinator for a program that supports young adults with autism spectrum disorders and other learning differences in gaining independence. The academic department works with students on everything relating to college,

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including enrollment, class selection, academic planning, tutoring, organization, and time management. Staff often spends about 25% of their one-on-one time with students supporting them through the process of requesting, obtaining, and utilizing disability accommodations. This adds up to 10-20 hours per term simply assisting students in accessing what they are already entitled to access.

IMPROVING EXECUTIVE FUNCTIONING SKILLS

Step number four above requires essentially every single executive functioning skill that exists in the literature! The flurry of form, deadlines, chains of command, and far-flung resource centers that suddenly burst into existence upon the approval of

BREAKING THINGS DOWN			
If you or a loved one on the spectrum is on the brink of making decisions about transitioning to a college or university setting, focus on the steps, potential barriers, and skills needed to accomplish each task.			
TASK	STEPS	POTENTIAL BARRIERS/DIFFICULTIES	EXECUTIVE FUNCTIONING SKILLS NEEDED
Attending Orientation	Locating center’s information, finding orientation times by calling or looking them up, getting to the orientation on time, retaining information given at orientation	Lots of information is given at once, both verbally and physically, individualized attention may or may not be given, and it may be anxiety-provoking to ask questions in a group setting.	Organization, time management, working memory, task initiation, communication, response inhibition
Documenting Disability	Obtaining documentation that meets requirements, delivering it to the center	If the student does not already have documentation, they must make an appointment with a clinician to obtain it. That process can take a long time and involve multiple visits if the practitioner is one the student has not seen before.	Organization, task initiation, goal-directed persistence
Requesting Accommodations	Assessing needed accommodations, filling out paperwork for each course	Which accommodations the student requests is up to the student, which requires a measure of self-awareness and willingness to work with center staff and professors. Sometimes it is not clear which accommodations are needed until after the class begins.	Self-perception and awareness, task initiation, communication, flexibility
Following up and Utilizing Accommodations	Letting professors know of accommodations, obtaining note-taking paper, following up with audiobook/ebook scans, keeping track of deadlines by which to schedule exams, making appointments with counselors for follow-up	Resources may be spread out over more than one building. Professors may not be aware of the processes of Disability Service Centers and may need reminders. All campuses may not have the accommodations a given student needs. There may be long lines on test days. Testing availability may not fit with student schedules.	All!

accommodations would overwhelm even the most organized student (and continues to overwhelm my staff and myself despite collective years of experience with the procedures).

There are, of course, many strategies designed to improve many executive functioning skills, particularly the ones that involve time management and organization. We teach several here, among them keeping a school binder with separate pocket dividers for each class, and dedicated spots for syllabi, Disability Services paperwork, upcoming homework, returned homework, and handouts; carrying both a paper schedule and an electronic schedule at all times and inputting every commitment and due date; setting phone alarms to serve as reminders for to-do lists, and planning each week, and in some cases, each day, at the beginning of it.

These strategies eventually do work for most motivated students, but I have noticed that the learning curve is steeper when dealing with Disability Services than with many other things. I believe that the difference in the learning curve is at least partially due to the fact that wading through the system requires, in addition to executive functioning skills, students to be well on the path to self-determination. At the very least, students need to have a well-formed understanding of themselves, their strengths, their challenges, their goals, and their needs.

THE PATH TO SELF-DETERMINATION

Many students beginning college—neurotypical students and students with autism alike—have not yet developed any of these things. For neurotypicals, though, the effect of not having done so is less damaging. Self-determination, for students on the autism spectrum, includes not only self-awareness, self-knowledge,



and self-acceptance, but also the ability to disclose and advocate, and perhaps most importantly, the desire to learn how to function in the world even if it is difficult, inconvenient, and requires learning about things in which the student has no inherent “special” interest. It requires them to display “a true desire to learn about themselves, their diagnosis, and how to get on with their lives”. This process can be visualized with Dr. Michael McManmon’s “Continuum of Growth” chart, which illustrates the path students on the autism spectrum typically take to self-determination.

Until this is achieved, delving into their diagnosis in a new light must feel like a chore for students, particularly as it tends to take place in an unfamiliar location and outside of a regular schedule. If they’re also accompanied by a constant rotation of strangers, they’re lucky—more commonly, they are left alone to figure things out. Without the intrinsic motivation of having, or at least wanting, a clear picture of how they work, coupled with a clear goal, why would the student put the extra effort into ensuring they have and are using disability accommodations?

It takes a lot of executive functioning skills and effort, and the end goal is something that was simply handed to them in high school. Most of our students, if not strongly discouraged from doing so by their academic coaches, would prefer simply to forgo the process and take their chances with no accommodations.

Supporting students through the transition between high school and college therefore requires not only the implementation of strategies designed to improve executive functioning skills, but a comprehensive support network that helps the student grow and progress towards full self-determination. This includes teaching the student about all sorts of different personality types, the promotion of authenticity, and drawing out confidence in owning their differences. Above all, it requires an atmosphere of acceptance. ◀

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