## **PREFACE:**

Usually, as high school graduation season commences and students get ready to move on to the next chapter in their lives and educational careers, I have offered some advice to parents of students with disabilities based on my own experience as a parent of a soon-to-be-college student with a disability more than a decade ago. Usually.

Nothing we are experiencing in this age of the pandemic is as usual. No one knows what to expect in the Fall. Indeed, colleges and universities are adopting different strategies to keep their students, staff, and faculty safe in the foreseeable future. There are no certainties, and there is no consistency! I assumed that my past advice to parents would not be useful in the face of our current, collective lived-experience. But when I went back to look at this "Open Letter to Parents of Students with Disabilities About to Enter College," I found that everything in the letter is still important to know and understand, even if some of it may be irrelevant for the Fall of 2020 (as it focuses on a traditional transition to face-to-face campus life). The problem is not that what is here isn't useful. The problem is that it is not enough.

With that in mind, then, I encourage you to read through the letter below, and then join me at the end to consider some additional concerns and considerations during this COVID-19 crisis.

Jane Jarrow

for us to step back and allow/encourage/gently nudge our SWD's (Students With Disabilities) to assume significant independent responsibility for their own lives, both academically and personally.

As you and your SWD prepare to visit campus for that initial meeting with a disability service provider at the college, you would do well to think about what can be accomplished at this initial meeting, what needs to be said — and who is going to say it!!! As I approach that same milestone with my daughter, I find myself a little panicky, realizing that there are things about her disability and how it impacts on her functioning that I know and that the disability services provider needs to know, and that I may not have many chances to say. There is no doubt that I can explain those things more fully than my daughter can explain them (or even understands them!). And it doesn't matter. Much as I hate it, I know that SHE has to be the one to convey all this crucial information (not me!), for a number of reasons.

First, colleges and universities provide services and support to SWD under very different laws than those that governed services in the K-12 system. As a parent, I have no rights under Section 504/ADA in speaking for my SWD who is in college. (If you aren't sure what "Section 504/ADA" means in this context, perhaps the disability service provider you meet with will have gathered some information that helps explain the differences between settings, both legally and practically. Two of my favorite websites for learning more are at:

<a href="http://www.ed.gov/about/offices/list/ocr/transition.html">http://www.heath.gwu.edu/</a>). The services and support available to SWD are sometimes very different than what was provided in high school, and the college is under no obligation to continue the services given in high school or to adhere to the recommendations of an outside diagnostician. The college will make its own determination of what services and support to offer, based on the documentation of disability and their interview with your SWD. There are no IEP's in college, there is no place to sign off with my parental approval. Indeed, the college doesn't legally have to care whether I am satisfied or

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You might say, "I was surprised to hear Jane say	I would have said	, because"
You'll get your point across without directly contract	dicting what your son/daug	ghter said. Your
goal is to assure both the SWD and the disability ser	vice provider that you are	supportive of their
budding understanding, and simply want to share an	other viewpoint.	

An old adage maintains: There are only two things a parent can give to a child... One is roots. The other is wings.

It is time for our kids to solo. That is a scary thought for us, as parents, and it is sure to be scary for them, too. That's OK. This is what we have all been working towards for a long time. Remember, your son/daughter will call, email, or text if they need you. They know what you can do for them, but now it is time for them to go it alone. Take a deep breath, cross your fingers, wish them well – and walk away. All will be well!

Best of luck, Jane Jarrow Proud (and Terrified) Mom JaneJarrow@aol.com

## **EPILOGUE:**

One of the first (and hardest!) lessons I had to learn in supporting my daughter through her educational career was the importance of sorting out my worries and concerns as the parent of a daughter with a disability, from my worries and concerns as a parent. I have to believe that will be even more difficult for you, in this atmosphere of uncertainty, than it was for me in a more stable and expected environment. But it will also be more important for you to recognize that distinction.

Were I you, I would be worried about the steps being taken at a residential institution to make sure that the living arrangements for the Fall were safe and appropriate in response to the current crisis. I would be worried about what limitations there might be on the events and activities that typically give the campus its flair and atmosphere, from athletic events, to Greek Life, to clubs and student organizations. I would be worried about the contingency plans in place if there is a resurgence of the coronavirus and face-to-face classes needed to be suspended (alternately, if the institution has already decided to move the Fall semester online, I would want to know how that was going to work). And I would worry about what kind of accommodations/support will be available for my SWD in transitioning to this altered version of a campus community.

All of those are valid concerns, but it is important to remember that the disability services folks are only in a position to answer the last of those questions – and that they are in the <u>best</u> position to give your SWD those answers. The contact your son or daughter has with the folks in disability services may look different than the scenario suggested in the Open Letter (above), but the Do's and Don'ts given there may still be useful, although modified slightly.

It is likely the initial interview will be done remotely, either through a telephone or video conference. That should make it easier to remember that the focus is on the interaction between your SWD and the service provider (as the SWD should be the one the camera focuses on!), but it does not mean that your role is diminished. In fact, this year you may have a more active role to play than under typical circumstances because you have some unique information to share.

- DON'T be insulted if the arrangements for the interview are made directly with your SWD instead of with or through you. Remember, this is their time to take the lead and establish a good working relationship with their new support network. But if you would like to sit in on that interview (and if it is alright with your SWD), why not say so. You might have your son or daughter contact the disability service provider and simply say, "My mom/dad will be with me for the interview." Then, when introductions are made at the start of the interview, you can say, "I realize this is your time to ask questions and get to know \_\_\_\_\_\_, but when you get to questions about the last few months and how things went during our home study period, I may have some useful information for you."
- DON'T begin any sentence with "S/He needs to have..." It was true before, and it is still true!
- DO take some time prepping your son/daughter in advance on the issues that you think need to be discussed. You can go back and read the suggestions in the original letter for this, but recognize that there will be some new things added this year. The disability service provider is going to want to know how your SWD fared when the schools were shut down this Spring, how your school district handled the shift to remote learning, what arrangements were made for accommodations or support for disability during this remote study, and how it worked out for your SWD. That information is critical both in understanding what the student's experience has been in online learning formats, and for determining what accommodations may be needed for online learning in the future. The conversation still needs to include all the questions about traditional face-to-face classes, as we hope that at some point those more traditional offerings will be the norm once again. But for now, we have to plan for a broader (potential) set of needs.
- DON'T interrupt. Go back and read that part again from the earlier letter. It's still important and necessary!
- DO prompt your son/daughter to speak up and share those important points as the
  interview progresses. As noted earlier, it is much better for the student to speak than for
  you to speak. Encourage your SWD with leading statements that help guide them to the
  issues that need to be raised. "Why don't you tell Ms. \_\_\_\_\_ about the problems you had
  taking timed tests on the computer. Why was that harder for you than getting extra time
  on a test when they sent you to the Learning Center at school to finish up?"
- DO be prepared, when the time is right, to say something along the lines of, "It was a challenge for all of us when the schools closed down abruptly and all learning was going on remotely. I am the one who was primarily responsible for supporting \_\_\_\_ during that time. I noticed..." Here is your chance to share some of those insights you have, not just about how things went when you were doing the schooling/supervision, but how what happened at home seems to compare with your understanding of what happened in school before the crisis.

Letting go is going to be doubly difficult this Fall – but it is still the right thing to do. I thought this quote might help to put things in perspective:

Trust the wait. Embrace the uncertainty. Enjoy the beauty of becoming. When nothing is certain, anything is possible.

Wishing you the best of luck in moving forward. Sincerely,

Jane Jarrow