Jane Jarrow's Letter to Parents

An Open Letter to Parents of Students with Disabilities About to Enter College

Dear Parents, I have been working in the area of students with disabilities at the college level for more than 30 years, but that is not why I am writing to you today. I am writing as a parent, and thus as someone who shares all your current anxieties. My daughter, who graduated from high school in early June, will be going away to college this Fall. She has Cerebral Palsy, uses a wheelchair, and has limited speech capabilities, so you can be assured that I have been very involved in the educational programming and planning she has received during her years in the public school system. I wanted to be involved, but I also needed to be involved since, by law, the school could not do anything for, to, or with my daughter regarding her disability without my permission. I sat through countless IEP meetings over the years, I was insistent on certain issues of academic support when I needed to be, and I agonized over everything from teacher selection to her successful social integration with classmates. And now, as I prepare to pack her up and take her off to college in the Fall, I recognize that this role has ended for me – and the word "anxious" doesn't even begin to describe my feelings.

If you are worried that your **child** with a disability will have a difficult time making a successful transition to college without your involvement… then you are probably right to be worried. Very few children with disabilities can succeed at the college level. On the other hand, **students** with disabilities survive and thrive on college campuses across the country. If you still think of your son or daughter as your "child," and they still are comfortable in accepting that role, it is time to take a careful look at where you have come from and what lies before you. As parents, it is time 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: http://www.ed.gov/about/offices/list/ocr/transition.html and http://www.heath.gwu.edu/).

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 not. My daughter is responsible for her own destiny now.

More importantly, while this may be your last chance to convey all that important information on to the college, it is your SWD's first chance to convey that information all by himself/herself. Don't spoil that opportunity, and don't interfere. Remember, while you and your SWD are learning more about the campus, the resources, and the people who will be there to help when needed, the disability service provider is learning more about your son/daughter, as well. You want their first impression to be one that is positive and reassuring. The service provider is anxious to find out whether your SWD is mature enough to handle the responsibilities and independence of college life. Here are some specific suggestions for helping your SWD to shine in this newly focused spotlight:

• DON'T be insulted if you are not invited to sit in on the initial meeting between your SWD and the disability services folks. Some institutions have found that it is helpful for them to speak directly (and alone!) to the student in order to get a feel for how knowledgeable and confident s/he is in sharing information about past services, what works and doesn't work, and what accommodations they hope to have at the college level. You will get a chance to ask your questions, but recognize that it may come later, rather than sooner.

• If you are invited to sit in on the meeting with the disability services folks, DO acknowledge your SWD as the authority on their disability-related needs by making it clear that you believe they have all the answers! Try focusing your visual attention on your son/daughter instead of trying to make eye contact with the interviewer. If you look to your SWD, so will the professional.

• DON'T begin any sentence with "S/He needs to have…" Instead, you can try, "In high school, s/he had…" or "The person who tested him/her suggested…" but it would actually be better if you said nothing at all! Try to talk as little as possible in the meeting. This is not your meeting. Remember, you are there as an observer, not as a participant.

• DO take some time prepping your son/daughter in advance on the issues that you think need to be discussed – the things that you would say if you had the chance. Make a list of the topics you would bring up, explain why you think each is important, and make sure your SWD has the list in hand when s/he goes into the interview. Rehearse with your son/daughter, if they will let you. If they are typical teens and aren't comfortable sitting through that kind of rehearsal, settle for making them sit and listen while you demonstrate how you would approach certain subjects. For example, "I think you should tell them about how the teachers arranged for extra time for you on tests when you were in high school. I'd probably say, 'In high school, I was allowed extra time for tests in English because it takes me a long time to put my thoughts in writing, but I never

needed it in Math.'" Your SWD may not acknowledge the strategies you share, but you may be surprised to hear those words come out of his/her mouth at the interview!

• DON'T interrupt. If you disagree with something the disability service provider says, or if your SWD says something that you know is incorrect, or if you see your SWD agreeing with/to something when you know they have no idea what they are agreeing to – DON'T INTERRUPT! Let the interview play out. Give the disability service provider a chance to draw your SWD out further, give your SWD an opportunity to clarify matters, or simply wait to see if the confusion/disagreement remains. It is important to know just how independent and accurate students are in describing their needs. You will get your chance.

• DO prompt your son/daughter to speak up and share those important points as the interview progresses. Instead of explaining to the disability service provider why Johnny needs a calculator in math classes, turn to Johnny and say, "Why don't you explain to Ms. ____ why it is important for you to have a calculator for math and science classes. Is it because you have trouble lining up the columns, or because you have trouble remembering basic math facts or ????" Give an open-ended question that encourages your SWD to flesh out the response. At the same time, you are hinting to the interviewer that there is an issue here to be discussed (See? I told you that you would get your chance!)

Why not take notes as the interview progresses? When your son/daughter has exhausted the list of topics to discuss, and the disability service provider has shared all the information they thought was important, it is YOUR turn to talk. Go ahead and ask your questions. The most important thing to remember now is that you do not want to undermine your son/daughter's credibility. If you have more information to share on a given subject, try starting the sentence with, "As Susie told you, she has used…" and then add whatever you need to on top of information already given. If you think your SWD gave incorrect information, tread carefully. You might say, "I was surprised to hear Jane say _____. I would have said _____, because…" You'll get your point across without directly contradicting what your son/daughter said. Your goal is to assure both the SWD and the disability service provider that you are supportive of their budding understanding, and simply want to share another 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