

“The Road to College – A GPS for Students with Disabilities”  
MDA Public Web Ex – February 24, 2010  
Hosts: Chris Rosa, PhD, L. Vance Taylor, Angela Wrigglesworth

### Follow Up Questions & Answers

*Following the Web Ex, participants were able to send questions to presenters; provided below are questions submitted by members of the MDA community, along with answers offered by our esteemed presenters. Please forward additional questions to [advocacy@mdausa.org](mailto:advocacy@mdausa.org).*

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#### **Q - How do you establish a good working relationship with personal care assistants (PCAs)?**

A – The following list was provided by Vance Taylor:

- **Set a respectful and friendly tone.** *Managing a PCA can be tough, but working through challenges is a lot easier in a courteous environment.*
- **Lead by example, stick to the schedule as much as possible.** *Want to sleep in? Chances are your PCA did too. If they got up to care for you, you need to get up too.*
- **Establish open lines of communication.** *You’re going to be working in extremely close quarters and if issues are not addressed early, they will fester. Ask your PCA about their concerns, frustrations, etc. and share yours too.*
- **Nobody wants to work for a jerk (enough said).**
- **Remember that you are the boss.** *Input from PCA’s regarding schedule, pay, time off, and perks is great, but you are the boss. Don’t be afraid to make decisions, just be sure they are made thoughtfully.*

A – The following list was provided by Angela Wrigglesworth:

- *Establish routines and expectations early*
- *Reward good PCA’s as much as possible with vacation time and bonuses (a Starbuck’s gift card can go a long way)*
- *Be flexible with schedules keeping in mind that a PCA has their own life, too*
- *Be in good spirits as much as possible*

- *Be patient and expect to repeat directions in a gentle tone of voice*

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**Q - Are there any specific scholarships for students with MD?**

*A - Unfortunately, there are few scholarships earmarked specifically for students with disabilities and none of which we are aware that are exclusively for students with neuromuscular disabilities. For other tips on funding college, please refer to the “Who’s Gonna Pay for All This?” slide in our presentation. (Chris Rosa)*

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**Q - What's the most important thing needed to survive college?**

*A – Attitude, attitude, attitude. Decide now that no matter what, you will leverage your college experience for all it’s worth. Decide now to make friends, have fun, get good grades, and make an impact on campus. You get one real shot to do this right; don’t waste it being shy or insecure. (Vance Taylor)*

*A - College is a tremendous opportunity to develop your “emotional intelligence” as well as your intellectual intelligence. It’s a chance to test your resilience and your ability to develop meaningful and supportive relationships with others. It is your ability to develop these capacities – resilience and interpersonal abilities – which will go a long way to determining whether you survive or thrive in college. (Chris Rosa)*

*A – Find great friends. (Angela Wrigglesworth)*

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**Q - How do you prepare for having others care for you instead of parent(s)?**

*A – The following list of suggestions was provided by Vance Taylor:*

- **Role play.** *Ask your current aide to pretend they are a new PCA, walk through the interview process and verbally instruct them on how to care for your needs – be specific.*

- **Learn to be flexible.** *While the core of your “routine” may stay the same, accept that there may be more than one way to do things. After having younger/stronger PCA’s in college, it was sometimes challenging to go home for the summer because I no longer liked how my mom used to do it. My how things change!*
- **Remember, everyone poops.** *Having a new PCA see you naked, care for your hygiene, etc. can feel embarrassing or awkward, but don’t let your needs go unmet! Your PCA poops, gets boogers, and has morning-breath too.*

A – The following list of suggestions was provided by Angela Wigglesworth:

- *Bring in a PCA to your parents’ home as soon as possible*
- *Ask a trusted friend or other family member to help you out once or twice a week*
- *Give your parents a “Weekend Off” and take a road trip (even if it’s just a day trip)*

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**Q - What's the best way to create a personal network of resources?**

A – The following was provided by Vance Taylor:

- **Be outgoing.** *Talk to people on the elevator, in class (not during the lecture), at the lunch table, etc. Particularly during the first two weeks of school, everyone is clamoring to make friends and meet people because everyone is on their own and in need of a social network. Be proactive about meeting your professors, the students with disabilities office personnel, and maybe most importantly people in your dorm.*
- **Be assertive.** *People may want to be your friend or go out with you, but may not ask you to participate because they don’t know your limitations. Take the lead and teach people how much fun you can be.*

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**Q – What are the most important resources at college?**

A – *Friends. Your friends will lay down in traffic for you so be good to them and make as many as you can!* (Vance Taylor)

*A - The Office of Disability Services is the key strategic resource in college. This Office will be crucial in assisting you with the coordination of your accommodations, help you troubleshoot access issues, and serve as general nexus of support around all manner of disability issues. (Chris Rosa)*

*A - Other students with disabilities- form a co-op of PCA's (Angela Wrigglesworth)*

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**Q - What services does MDA have to help in planning?**

*A – MDA's supports and resources are designed to start when students are elementary school age and gradually continue throughout the transition to college and into adulthood. Beginning with resources available at [www.mda.org/advocacy/school](http://www.mda.org/advocacy/school) and extending through local MDA Health Care Service Coordinators, families have access to print publications that are geared towards school personnel, guidelines for considerations when creating IEPs and 504 plans, classroom presentation outlines and presenter support, MDA's Roadmap to Independence to facilitate dialogue about the multitude of issues involved in transitioning to adulthood, and checklists and resources specific to the college selection process. For specific questions or needs, please contact your local MDA office or email MDA's Advocacy team at [advocacy@mdausa.org](mailto:advocacy@mdausa.org). (MDA)*

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**Q - How do you make yourself employable?**

*A – Evaluate your interest areas and identify the competitive fields in that area. Next, study hard – you need to know your stuff cold. Seek advice from professors, ask them how one succeeds in the field of your choice. A major first-break comes from doing an internship; identify the job/company of your dreams and intern there. Do a good job and you can nearly guarantee employment there after graduation. Smart companies want to hire qualified persons with disabilities, help them by doing a bang- up job as an intern. (Vance Taylor)*

*A - One reason why people with disabilities – even those with college degrees -- continue to struggle to find competitive employment is because*

*they are often excluded from opportunities to acquire the work experience, “soft-skills”, and understanding of workplace culture that are key to acquiring and maintaining employment. College offers great opportunities to build these capacities. Work-study, volunteer, and student leadership opportunities are great ways to build the cultural capital necessary to be competitive and successful in the world of work. (Chris Rosa)*

*A – When selecting a career path, pick a field that you’re good at. Then, when pursuing job prospects, isolate your needs in the workplace ahead of time so that your future employer knows in advance what they will need to provide in order for you to be successful. (Angela Wrigglesworth)*

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**Q - I'm in 11th grade currently. What things do I need to start considering? When should I start doing college visits?**

*A – Nail your SAT/ACT, etc. Take the prep courses; they work. Get good grades, join clubs, do community service, etc. Look for ways to build your resume and make yourself into a more competitive college applicant. Select your top two colleges, visit if you can, and two backups – apply to all four. Remember, you can always turn down offers. If you can visit the college before applying, great. If not try and go upon your acceptance, but your first priority needs to be getting accepted, hopefully to the school of your dreams. (Vance Taylor)*

*A - Spring break of Junior year of high school and summer between Junior and Senior years are good times for campus visits. (Chris Rosa)*

*A – Please visit the resource links at [www.mda.org/advocacy/school](http://www.mda.org/advocacy/school) for considerations checklists and resource links. (MDA)*

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**Q - What things should be considered in choosing housing? What is/what are your opinion(s) on the different options?**

*A – If possible, start by living in the on-campus dorms. Socially, you’re going to have a blast. From a practical perspective being on campus means the university is at your finger tips, classes are closer, you don’t have to worry about cooking, there will always be someone around if you need help, etc. Overall, on-campus life gives you a much greater opportunity to enjoy a more independent lifestyle. (Vance Taylor)*

*A – If you can use the toilet and take a bath there- it’s perfect!! Living on campus the first year or two is very helpful. Afterwards, if you have great people to live with and a safe, accessible apartment, then off campus living prepares you for the real world. (Angela Wrigglesworth)*

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**Q - What is an IEP or 504 Plan?**

*A - For students in K-12, access and opportunities are governed by the Individuals with Disabilities Education Act (IDEA) and Section 504 of the Rehabilitation Act. Under the IDEA, students with significant accommodation and service needs have them addressed through an Individualized Education Plan (IEP) which outlines the academic adjustments and support services that must be provided to ensure student success. Students with significant accommodation needs (i.e. wheelchair-accessible desks, access to the school elevator, etc.) have their needs addressed in accordance with Section 504 via “504 plans” which simply outline students’ accommodation needs. (Chris Rosa)*

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**Q - Could you please share one thing that wasn’t covered during the WebEx that you wish you had known before you chose a college?**

*A - I wish I would’ve made better choices with eating. Because I was now eating out more often, I gained a lot of weight and it took me many years to take it off. (Angela Wrigglesworth)*

*A – Ditto, watch it with the weight gain. Not kidding! (Vance Taylor)*

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**Q - Are there any other suggestions for working with PCAs?**

A – The following suggestions for finding, hiring, and managing a PCA were provided by Angela Wrigglesworth:

- When seeking a Personal Care Attendant on campus, you may want to work with the Office of Student Life or the Disability Services Office. Other good recruitment options include posting ads on online message boards and in bathroom stalls – you may also want to consider posting ads in places where they will be seen by nursing/medical students and students of other clinical professions. Being a PCA can be resume-building for students pursuing a clinical career path.

Suggestions for items to include in your ad:

- If you are in need of medical care, specify that experience is needed. If you do not require skilled nursing care, specify that no experience is needed.
- If the position is an overnight position, specify whether the PCA will be able to sleep throughout the night. In my case, while I need someone to help reposition me once or twice throughout the night and in the event of an emergency, my PCA generally gets a full night's sleep.
- Specify that the hours are flexible if you are able to work around a PCA's class schedule.

Suggested practices for screening and hiring applicants:

- First screen should be a phone interview
- When moving to the second interview phase and conducting the in-person interview, arrange to meet in a public place. You may also want to have a friend accompany you.
- During the interview, be sure to ask the following questions of the applicant:
  - ✓ Are you someone who gets sick easily?
  - ✓ Are you physically capable of performing the job?
  - ✓ Do you live nearby in case of an emergency?
- Check references
- Conduct a criminal background check (local MDA staff can help you figure out what the process is for getting this done in your state)
- It is also good to have a back-up PCA in case of emergencies

Suggested tips for being a successful manager:

- Always remember that you are the boss.
- Beginning on day 1, set up a protocol of clear expectations
- Determine the steps necessary for calling in sick.
- Provide your PCAs with contact information for your emergency contacts.
- Strive to maintain a pleasant work environment for your PCA – nobody wants to work for a mean or grumpy boss. Try and be in a good mood around your PCA, take his/her preferences into account, etc.

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**Q - Do you have suggestions about hiring a PCA when needs are unpredictable (such as periodic bouts of paralysis)?**

*A – If possible, hire someone that lives within 5 minutes (same dorm/apartment) and then have a friend in class that can help with emergencies. (Angela Wrigglesworth)*

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