## Personal Care Attendants and Students: An Introduction and Guide



Annie Tulkin, MS, Accessible College L. Scott Lissner, The Ohio State University

## Annie Tulkin, Accessible College

- Professional career in the disability field
  - Association of University Centers on Disability (AUCD)
  - ADA Compliance/training for Job Corps, Department of Labor
- Masters in Special Education from the University of Wisconsin, Bachelors in Secondary Education from DePaul University, Certificate in Health Coaching from Georgetown University
- Peace Corps Volunteer and Fulbright Fellow
- Nearly 6 years as the Associate Director of the Academic Resource Center at Georgetown University (Georgetown's Disability Support Services Office)
  - Supported undergrad, grad, and medical students with physical disabilities and health conditions with their accommodations and provided academic support services to the entire student population



### L. Scott Lissner, The Ohio State University

### The Ohio State University:

- ADA Coordinator and 504 Compliance Officer
- Associate, John Glenn School of Public Affairs
- Lecturer, Knowlton School of Architecture, Moritz College of Law & Disability Studies



### **Professional Appointments:**

 Chair, Public Policy Committee and Past President of AHEAD; Professional Advisory Committee, Disability Empowerment; Board VSA Ohio; Columbus Advisory Council on Disability Issues.

# Agenda

- Legal aspects
- Understanding the role of the PCA
- Understanding what students and families know/don't know about PCAs and college
- A day in the life: examples of students with PCAs
- Best practices
- Resources
- Questions



# Legal Considerations: The Boundarie

#### **Presence of a Personal Care Attendant**

- On campus (grounds and buildings including classrooms and residences)
  - Modification to Policy absent Undue Burden or Direct Threat a reasonable accommodation.

#### **Direct and Associated Costs**

- The institution is not responsible for the costs (salary, living expenses, parking permits...) of a Personal Care Attendant.
- Scope of parking permit, background checks and similar expenses required by the instatition are generally an institutional responsibility.
  - <u>28 CFR § 36.306</u> <u>28 CFR § 35.135</u> <u>34 CFR § 104.2</u>

#### Who Can be A Personal Care Attendant

- Professionals, Agency Staff, Family, Friends
- Medicaid allows payment to family members in most states
- Not all bad ideas are prohibited



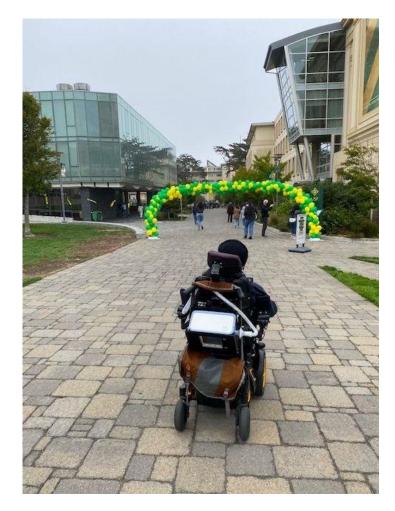
### Legal Considerations: The Boundaries

#### **Liability Concerns**

- Consider state law
- Others Establish applicability of Code of Conduct and/ or Vendor Rules
- Background checks
- Clarify Responsibilities and expectations
- Leisure Access Guest privileges
- Emergency Planning from the flu to evacuation

#### **Overlapping Roles**

- Lab Attendants
- Voice
- Scribe
- Reader



### **Policy Review**

PCAs should be licensed, bonded and insured professionals. A student requesting a PCA who is not a professional care provider will need to discuss the situation with his/her accessibility counselor. Approval for PCAs who are not professional care givers will be provided if in the determination of the Director of the Counseling Center this is necessary. No more than three (3) individuals per student can be listed and provided access to serve as PCAs.

To live in XYZ College housing, students with a disability who require the assistance of a PCA must secure these services at least four (4) weeks prior to the start of the semester.

## **Policy Points of Concern**

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## **Examples of PCA Policies**

### **Oregon State University**

### Pomona College

- Clear and comprehensive
- Outlines roles for disability office and student
- Integrates university policy (code of conduct, academic honesty, etc)
- PCA vs. lab assistant
- FAQs for faculty re: classroom engagement

- Clear and comprehensive
- Outlines roles for disability office and student
- Integrates university policy (code of conduct, academic honesty, etc)
- FAQ's for faculty
- PCA agreement form

## Understanding the Role of a PCA

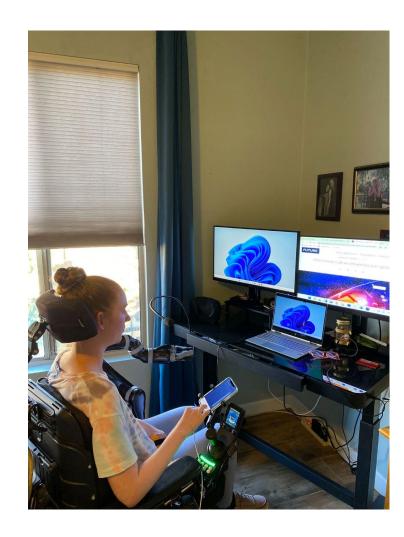
- Activities of Daily Living:
  - Dressing, bathing, grooming, eating, positioning, toileting
  - Shopping, housework, laundry, meal preparation
- Health Related Support:
  - Medication administration, catheter care, bowel care, respiratory care
- In the Classroom/On campus:
  - Setting up area for student, getting things from bag, support with food/drink, transportation, assistance with navigation



### In the Classroom

#### Oregon State Guide

- Engage the student in the interactive process:
  - What do they need support with in the classroom?
  - How has classroom support worked in the past?
- Types of assistance
  - Getting books and laptop of of bag
  - Support with communication
  - Medical assistance with ventilator, drinking, medication, etc
- FAQs for faculty/staff on how to work with the student and the PCA
  - Provide guidance for faculty/staff
  - Encourage a conversation between the student and faculty member



### **PCA Access**

#### On Campus

- Dining Hall
- Library
- Recreation
- Transportation

Will the PCA have access to all of these places? What are the perimeters?

#### Off Campus

- Class related field trips
- Sport Events
- Study Abroad
- Internship/practicum/student teaching



## **Prior to College**

## **Personal Care in High School**

- Individualized Education Program (IEP)
  - Provides for services: PT/OT, Aide, O&M, etc
  - Covered by the school
- Skilled Nurse, Paraeducator, Aide
  - Assistance in the classroom
  - Assistance navigating building
  - Toileting
  - Eating
  - Medication/respiratory care
- Takeaway: Many families are unaware that colleges do not provide PCAs and they are not aware of the change from IDEA to ADA (loss of services)

## Financing a PCA

It's EXPENSIVE!

• The cost of care varies from state to state

Types of Care Providers:

- Home Health Agency
- Private Hire (including hiring students)
- Family member/friend
- Hybrid: variation of the above mentioned providers

Sources of Funding:

- Supplemental Security Insurance
- State Vocational Rehabilitation
- Medicaid
- Private Funds (Personal finances, ABLE Accounts)
- Scholarships (outside or college based)
- Disability related financial aid appeal

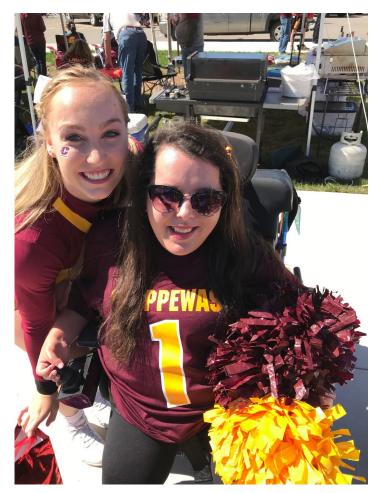


# Hiring a PCA

- Students responsibility
- Challenges of being 18 and an employer
- Making the Move to Managing Your own Personal Assistance Services(PAS) A Toolkit for Youth With Disabilities Transitioning to Adulthood: Toolkit from U.S. Department of Labor, Office of Disability Employment Policy to guide young adults on hiring, monitoring, personal care attendants.
- Using an Agency=more expensive, but potentially more reliable
- Private Hire(s)=train, hire, and manage

## In Their Own Words

Lauren Presutti: "I qualified for community living supports through Medicaid, which was coordinated through my local community mental health system," says Presutti. She explains that though her disability only affects her physically, she still qualified for services because of how Medicaid lumps different types of disabilities together. "Using the Medicaid system was extremely advantageous to me, and I would recommend checking out the options for Medicaid within your state because you will likely be able to find funding for caregivers if you need them," she says.



## In Their Own Words (2)

"I found my PCA through a local nursing school program. I'm able to fund that through a scholarship that I receive," says Kate Solliday, a student at Arizona State University who had a stroke and lives with a spinal cord injury.



### In Their Own Words (3)

Kayvan Zahiri is a first-year student at the University of San Francisco who has spinal arteriovenous malformation. "I have a nurse that works with me and accompanies me to school. The funding is through California Children's services MediCal," he says. "When hiring someone as a PCA, it's good to set up a meet and greet prior to making any decisions to see if it's a good fit. Fortunately, I have worked with the same nurse for years, so I didn't have to find a new person." Before school started, they toured the campus together so they could both have a better idea of Zahiri's support needs in the new environment.



## **Sample Routines/Job Description**

Sample 1: Joe

Sample 2: Jane

Sample 3: Maria

Job Description Sample

## **Best Practices**

- The role of the "interactive process" in understanding the students needs
- Fostering independence
- Respecting rights
- You don't what you don't know and that's OK! Connect with AHEAD colleagues!

### Questions



## Contact

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