AGENDA

- Introductions
- Study Background and Methodology
- Findings
  - Themes of Disempowerment
  - Themes of Empowerment
- Recommendations
  - Family, Students, Higher Education Professionals
- Discussion
  - Implications for Practice
  - Implications for Future Research
High School

Student Road Bumps
- e.g., communication skills, time-management, self-care

Family Road Bumps
- e.g., FERPA, college policies, transition from a caregiver role

Student Rest Stops
- e.g., transition planning, office of disability services, faculty training, UDL, support groups

Family Rest Stops
- e.g., orientation breakout sessions, family workshops, student-centered communication

Francis & Duke (2017)
“It's a constant fight. And it always happens. Even today. It happens all the time.”

“...I had to advocate for myself when I started college. Usually my parents were my advocates throughout my education and then when I started college it was just me on my own. That's another thing for [students] to know: to be there as their own advocate. Don't just shy away from your disability and everything.”
STUDY BACKGROUND: PARTICIPANTS

- 8 interviews
- 60% female
- 62% white
- All but 1 participant spoke English as first/ preferred language (Kurdish)
- 18-60 years
- Primary disability: mental health, specific learning disabilities, hearing impairment, visual impairment
STUDY BACKGROUND: METHODOLOGY

• Convenience sampling for initial researcher-developed online survey:
  • College students with disabilities
  • Registered with Disability Services Office
  • Large public University in mid-Atlantic region of US
• Survey asked participants to provide contact information to participate in a follow-up interview about their experiences
  • 109 survey respondents
  • 23 provided contact information for follow-up interview
  • PI attempted to contact each individual to schedule interview
    • Maximum of 3 attempts made over 3 weeks
    • 1 email invalid, 13 did not respond, 1 was no longer able to participate, and 8 scheduled interviews
Interviews were conducted:
- 1 in person
- 4 on phone
- 3 via Skype or Facetime
- 1 researcher facilitated interview while the 2nd recorded field notes and asked follow-up questions
- All interviews conducted in spoken English (no accommodations needed)
• Started each interview by explaining the purpose of the study and related risks and benefits, then obtaining written informed consent, including participant permission to record the interviews.

• Semi-structured protocol included questions related to:
  • Background information
  • Experiences in high school
  • Experiences in college
  • Recommendations to facilitate student success
  • Recommendations for families to prepare individuals with disabilities for college
FINDINGS: CYCLES OF EMPOWERMENT AND DISEMPowerMENT

Disempowerment → Empowerment

Empowerment → Disempowerment
FINDINGS:

DISEMPOWERMENT CYCLES

- Discouragement
- Debasement
- Insecurity
- Isolation
FINDINGS: DISEMPOWERMENT

DISCOURAGEMENT

• “I was excited. Somebody that understands disabilities and I'm going to go in there and show them my work to get feedback on how I can process this correctly and how I can get my thoughts out and all that stuff…The only thing she did for me was show me a web and I started crying because I was like once again, I have been disappointed. How can you advertise writing for disabilities and that person not be somebody who specializes in that?”

• “If I didn't advocate for myself and allowed once again to be disempowered…It's a constant fight. And it always happens. Even today. It happens all the time.”
“When I first was diagnosed and I brought in my paperwork to get accommodations, the first person I met with in the disability office literally said to me that she would never have diagnosed me with disabilities. She said, “I would never have diagnosed you with any disabilities. I think it's just because it's been a while since you've been in school.”
“Like I thought I was up here and actually I'm down here and I need some assistance... For students with disabilities... you think that you're on the same playing field and that's not reality.”

“They put me into a regular 3rd grade class and then stuck me in the back of the room and nobody helped me... I still play in my head the experiences as a child and what I felt growing up. Little things that happened and even in my math [class]- the [professor] rearranged the seats and put me next to students that were really good in math. I just broke down and cried because I literally was that 3rd grader all over again, put in the back of the room.”
FINDINGS: DISEMPOWERMENT

ISOLATION

• “My parents are still very much learning all about what America is. And to them having a child who's disabled from their frame of understanding is God's punishing us. We did something wrong- any person with disabilities, in most of the Middle East, they keep their child home. Whether you're Blind, you're Deaf, you're Autistic - they just - hidden is kind of the way they go.”
FINDINGS: 
EMPOWERMENT CYCLES

• Diagnoses
• Effective supports
• Family support
• Resilience
FINDINGS: EMPOWERMENT

DIAGNOSIS

• “Now I can tell people that I do have [autism]. This is me.”
• “I cried because I was like, I'm not stupid!”
• “When I got diagnosed at first I didn't really talk about it. But then I don't know, I felt like I'm not ashamed of it. I'm not ashamed of my disabilities and I'm not afraid to tell people.”
FINDINGS: EMPOWERMENT
EFFECTIVE SUPPORTS

- Specific support services and accommodations
- Priority registration
- Individualized academic or mental health services (e.g., take-home tests, posting recorded lectures and course materials online)
- Educators “who went beyond the accommodations,” and were “caring,” “warm,” “fun,” and “understanding” led to feeling of long-term support and empowerment
FINDINGS: EMPOWERMENT
FAMILY SUPPORT

• “...my dad understands because he went to high school in [State]. And so it's just the contrast of cultures and things so I run into that sometimes. But I've been better at hey, I need to go out for my own social health and wellbeing. Let me go.”

• “…empowering” students to “speak up [and] take back her power.”
FINDINGS: EMPOWERMENT

RESILIENCE

• “…I know if I don’t advocate for myself nobody else will. That's the reality, right?”

• “If I didn't advocate for myself and allowed once again to be disempowered…It's a constant fight. And it always happens. Even today. It happens all the time.”
YOUR THOUGHTS AND EXPERIENCES
RESULTS: RECOMMENDATIONS

Students

Families

Professionals
RESULTS: RECOMMENDATIONS FOR STUDENTS

• “If I want to go to a friend's - if I want to go to the mall with friends, [mom’s] like who, what, when, where, why, how? Are your friends driving? No. Let me drive you.”

• “two seminars: one for parents and one for kids so that the kids learn that they need to be independent and make sure that they have the resources available and tell the same thing to the parents but in a different seminar.”

• “…I had to advocate for myself when I started college. Usually my parents were my advocates throughout my education and then when I started college it was just me on my own. That's another thing for [students] to know: to be there as their own advocate. Don't just shy away from your disability and everything.”
RESULTS:
RECOMMENDATIONS FOR FAMILIES

“I was prepared for that. It's just I think when I got a point where I was in college now and now I have to do it on my own. That was kind of scary at first. I was already prepared because throughout my education my parents and the teachers I had - they told me I had to be able to advocate for myself. I had to do it. So I started doing that now.”
Community & Inclusiveness

• “Create a community within the disabilities for students to find people like themselves” to reduce students feeling “very alone and isolated.”

• “Colleges/universities should be more inclusive for people with disabilities [to] be able to better understand his/her disabilities.”

• Rename DSOs “using a more positive, approachable name [such as] the Learning Center” in order to “encourage students to seek help and resources from the office.”

• Create a safe space for mental health support
RESULTS:
RECOMMENDATIONS FOR HIGHER EDUCATION PROFESSIONALS

Faculty and Staff Training & Supports

• Encourage “professors to automatically email disability disclosure forms to each student at the beginning of the semester;”
• Teach professors “to not treat disabled students like cheaters and demand medical records;”
• Provide “continuing education for professors to help spot students with learning disabilities;”
• Train tutors to better understand how students with disabilities “learn differently;”
• Teach professionals how to “be patient” with students with disabilities,
• Train college faculty and staff how to handle mental health crises
DISCUSSION:
IMPLICATIONS FOR PRACTICE

• Professional Development
• Family support and resources
• University freshman seminars
• Universal screening in universities
• Peer groups [isolation reduction supports]
DISCUSSION:
IMPLICATIONS FOR FUTURE RESEARCH

• Diversity in research studies
• Study replication for specific disability populations
• Perspectives of families and education professionals
• Diagnosis research/implications
• Inclusion and isolation
• Influence of family interactions
  - Cultural considerations
OTHER QUESTIONS?

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