

PROCEEDINGS

ROUNDTABLE

CHRONIC MEDICAL DISABILITIES
& HIGHER EDUCATION

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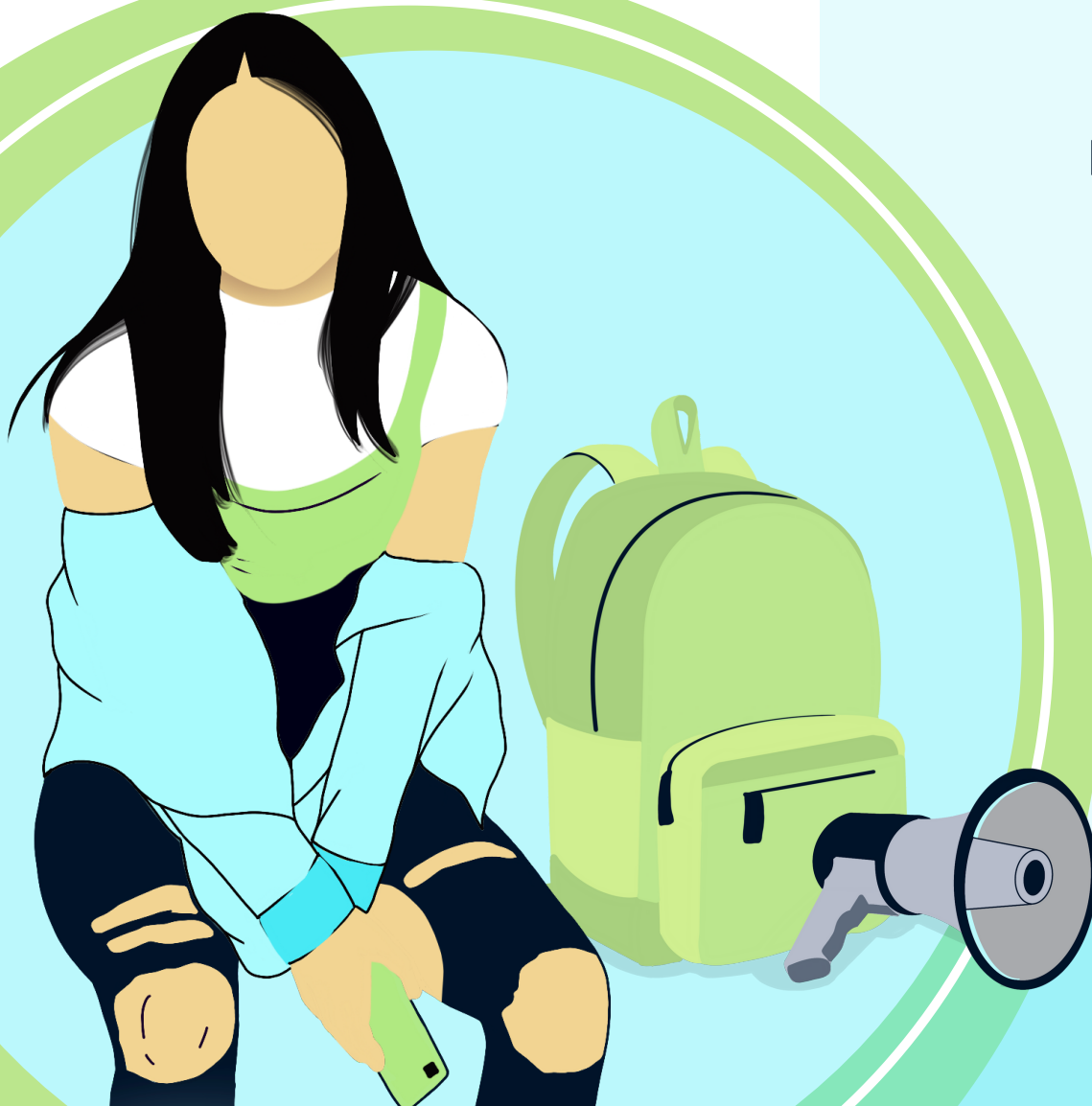




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This Roundtable was hosted by Generation Patient, a nonprofit organization led entirely by young adult patients. Our work is dedicated to empowering adolescents and young adults with chronic and rare conditions (chronic medical disabilities) through the facilitation of events and online programs.

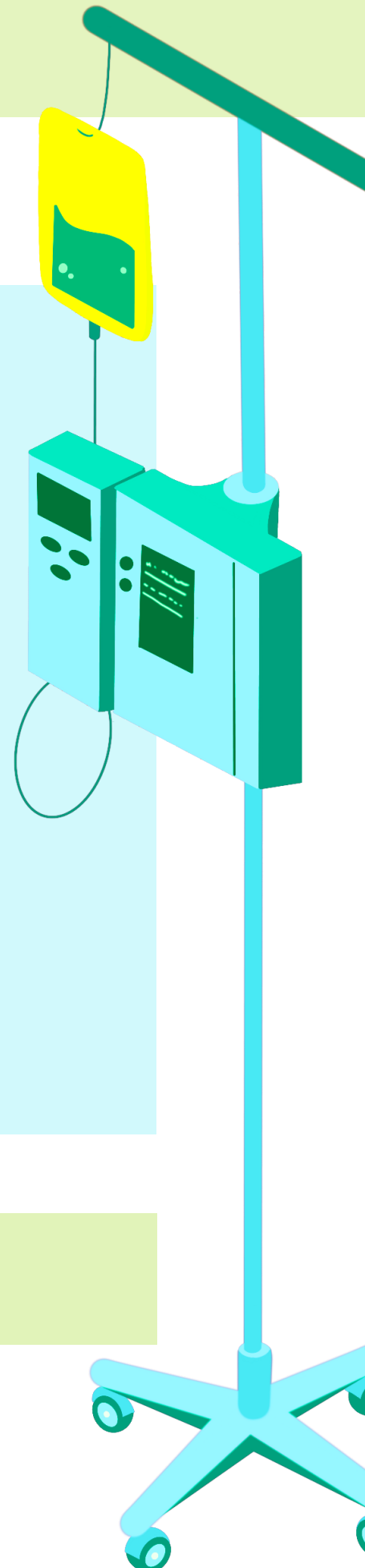
We would like to acknowledge the following individuals for presenting:

Elijah Armstrong
Betsy Basch
Richard Allegra
Lizzie Cremer
Nathan Burns

Gerry Altamirano
Eiryn Griest Schwartzman
Syreeta Nolan
Alicia Wackerly-Painter

Rapporteurs:

Amy Bugwadia, Sneha Dave, Sydney Reed



Part One: Introduction

Chronic conditions in adolescence are increasing as larger numbers of chronically ill children survive beyond the age of 10.

While adolescent and young adult patients are at a critical point of development and transition, there is a significant lack of support for this growing demographic as they enter adulthood. Generation Patient is a nonprofit organization led entirely by young adult patients and dedicated to empowering adolescents and young adults with chronic and rare conditions (chronic medical disabilities) through the facilitation of events and online programs. There is a scarcity of awareness, research, and resources at the intersection of higher education and chronic medical conditions that must be addressed. We spearheaded our first Roundtable on Higher Education and Chronic Medical Disabilities as an initial effort to help bridge this gap. This Roundtable brought together both students and higher education professionals in order to recognize the unique learning and socioemotional needs of college students with chronic medical disabilities as well as the current barriers within the higher education system. We hope that the information summarized from these discussions will help to support the formation of a more accessible infrastructure within the realm of higher education.

An Urgent Need

Individuals diagnosed during childhood or adolescence face a lifetime of illness, the impact of which has not received adequate attention. The financial burden of a chronic illness alone can be massive. Twenty-three percent of chronically ill patients interviewed by the Harvard T. Chan School of Medicine reported being unable to

pay for basic necessities like food and housing (Being Seriously Ill in America Today, 2018). A study from 2017 reported that the mean annual total costs for people with lupus can be as high as \$50,000 each year (Barber & Clarke, 2017), and those diagnosed with Crohn's disease between the ages of zero and eleven years old could incur an average cost of over \$700,000 during their lifetime (Lichtenstein et al., 2020).

This is compounded by the fact that such early illness can lead to fewer years of education, more joblessness, and lower pay. The reality is that the financial security—and thus, continued survival and quality of life of those diagnosed with chronic conditions as children and young adults—can be significantly impacted by their ability to pursue and complete postsecondary education.

Unfortunately, students with chronic medical disabilities face unique challenges that create barriers to the career and higher education opportunities they desperately need. Such barriers include, but are not limited to, having invisible or non-apparent conditions, the unpredictability and continuously fluctuating severity of many chronic medical conditions (dynamic disabilities), and the lack of education and understanding of chronic medical disabilities by university staff and administrators.

These unique challenges mean the support needs of these students are also distinct, but the standard

accommodations do not typically provide adequate support for these students. Furthermore, the stigma often experienced by students with chronic conditions encourages them to refrain from disclosing their condition or asking for help, even if it hinders their educational opportunities or leads to further isolation and lack of support.

Students with a chronic medical condition are entitled to equitable access to education, despite the severity or acuity of their condition and despite the inherent challenges or burdens – actual or perceived – associated with providing them a quality education (for Students with Health Conditions, 2017). There is a substantial lack of research and resources at the intersection of higher education and chronic medical conditions that must be addressed.



Part Two: Accommodations – Existing Structures and Opportunities for Change

The second part of the Roundtable included personal and professional perspectives on how to promote a culture of understanding and support for students with chronic medical conditions, both by tackling common misconceptions about these students and by providing resources to students, faculty, and administrators for further learning and action. Speakers included Elijah Armstrong, a self-advocate and creator of Equal Opportunities for Students; Betsy Basch, a Mental Health Programs Specialist; and Richard Allegra, Director of Information and Outreach for the Association on Higher Education and Disability (AHEAD). The following highlights key information from the sessions about the existing ableism in higher education and productive conversations on working to transform the higher education system.

Elijah Armstrong (he/him)

The first speaker, Elijah Armstrong, identifies as an epileptic who faced systematic challenges in navigating accommodations at his high school, a top public magnet high school in the nation. As he described, during his junior year, the lights in the classroom started to flicker, causing seizures and making him severely ill, causing him to frequently go to the hospital. Armstrong requested accommodations in order to not have to sit in that classroom, including an attempt to change his classroom or

to take the class online. However, in writing, his high school stated that they did not do accommodations. The school was so adamant about not providing accommodations that he was told he would have to leave the school. This incident happened during his junior year of high school, a pivotal year where planning for post-graduate success occurs

The incident, one he cites as a critical part of his high school career, had large implications as he was considering higher education. As Armstrong applied to higher education

institutions, he articulated his concern about not getting accepted into schools. Armstrong was refused makeup work from his school which resulted in significantly lower grades.

In recounting systemic barriers, Armstrong highlighted earning scholarships was an added challenge. The toll of epilepsy on his body prevented him from participating in fewer extracurricular activities, and the GPA requirements for scholarships made it hard to apply, given his school did not provide adequate accommodations. Furthermore, ableism impacted getting letters of recommendation from teachers. Armstrong also noted that many colleges require a letter of recommendation from a student guidance counselor. Armstrong's guidance counselor also happened to be the 504 designees for the school, which had numerous implications and conflicts of interest.

Armstrong noted that he was still top 50% in class, despite being forced to fail classes. He cautioned that when students are funneled out of school, it is not an issue of capabilities, but rather one of school bias.



As a result of his experiences with ableism as he was considering pursuing higher education, Armstrong created Equal Opportunities for Students to help marginalized students, particularly disabled students, to ensure they have the resources they need and to help educate educators, teachers, and professors about what students with disabilities experience and the ways that they can be better supported.

In 2021, Armstrong was awarded the American Association of People with Disabilities Paul G. Hearne Emerging Leader award. As part of his project, Armstrong partnered with the Coelho Center to create the Heumann-Armstrong Award, an education award for students in sixth grade and up. The Heumann-Armstrong award selects 6 winners and 6 semi-finalists to receive scholarships to fight against ableism.

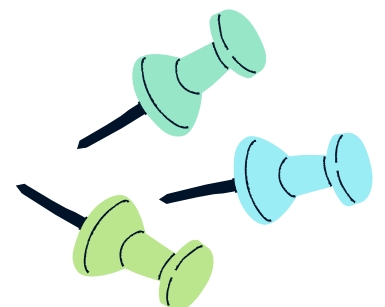
Key takeaways from Armstrong's presentation include the following:

- ▶ Ableism in school is a near-universal experience for disabled students.
- ▶ Schools often perpetuate these systems, as many schools often do not give proper or correct advice.
- ▶ It's important to have a network of people outside of school who can provide peer support and validation.
- ▶ It is important to advocate but also recognize that there are times when schools do not act in the students' best interest.

Betsy Basch (she/her)

Speaker Betsy Basch started off her presentation by sharing that she is someone with lived experience with disability and that she receives a variety of accommodations as an adult. Basch has worked in various educational formats, from post-secondary, charter school networks, prison schools, residential treatment schools, and traditional schools. Early on in her presentation, she highlighted the fact that her ability to be successful and present has largely been dependent on whether she had the appropriate accommodations in place.

Basch worked at the University of Illinois, where she promoted disability advocacy. The University of Illinois was the first postsecondary institution to offer adaptive education. Basch highlighted the fact that inclusive language and guidelines are critical to creating a culture of inclusion



She pointed out the differences between allyship and awareness; for example, while there was an LGBTQIA+ ally program at the University of Illinois, there was no specific disability ally program.

Basch continued to describe empathic modeling, an exercise that might celebrate or model what it is like to have a disability. The experience with empathic modeling is inaccurate or incomplete, individuals end up having more stereotypical attitudes afterward than before the experience. To illustrate her point, she asked, “We wouldn’t try to model what it is like to be part of other social identities, so why would we do it by trying to model a disability?” Basch indicated that an exception to this is for architectural design students who need to model whether buildings are accessible for people with certain disabilities.

Basch also noted that there was a continued curiosity of professors and students to experience what disability looked like. She and her team taught professors why this was problematic and developed disability education seminars for disabled and non-disabled students.

Further, Basch and her team conducted courses on campus and presented to committees such as the LGBTQ, Diversity programming committee, RAPE awareness prevention, Inclusive education, Counselor center, Intercultural relations, and academic advisors, in order to promote an understanding and active practice of disability allyship.

Richard Allegra (he/him)

The final speaker of the Accommodations Discussion was Richard Allegra, the Director of Information and Outreach for the Association on Higher Education and Disability (AHEAD), an association of professionals working in Disability Resources and Services in post-secondary settings. AHEAD engages in the professional development of members, sponsors research and scholarship, and promotes disability DEI in higher education.



Allegra works on a grant-funded project with the National Center for College Students with Disabilities (NCCSD), a federally-funded national resource center that includes technical assistance, research, and the DREAM program. Disability Rights, Education, Activism, and Mentoring (DREAM) is a national organization for and by college students with disabilities. DREAM serves as an online virtual disability cultural center for students who want to connect with other students. The NCCSD also houses a Campus Disability Resource Database (CeDaR), though Allegra did mention that there is currently not adequate information on students with chronic illnesses in the CeDaR database.



Allegra highlighted the issues that students with chronic illnesses may face, including:

- Students' fear or reluctance to use disability resource services (DRS), stems from the worry that they're "not disabled enough"
- Need to establish trust with the DRS
- Faculty suspicion of the legitimacy of students' chronic illnesses
- Rigid academic or campus policies

Allegra mentioned that the ways to address this include:

- Increased outreach to all students about DRS (i.e. brochures, websites, videos) which includes the wide variety of what disability can look like
- Increased training of DRS through organizations such as AHEAD
- Increased faculty training and awareness of disability
- Educating students about their civil rights, given the fact that the Americans with Disabilities Act (ADA) is a civil rights law
- Advocacy around flexible design of policies, practices, campus environments

Academic	Campus Environments
Attendance	Housing
Assignment Details	Dining Services
Class Activities	Gathering” Spaces
Note-taking	Wellness Spaces (i.e. on-campus sensory rooms for autistic students)
Exams	Financial

In the chart above, Allegra highlights various design areas to consider and address within both the Academic and Campus Environment, including:

Allegra alluded to an article by [Barber, D. & Williams, J.L.](#) that looks at chronic illness in female college students. The results indicated that the majority of participants identify their chronic illnesses as having a serious impact on life, school and social interactions. However, the majority have a positive outlook on their futures, but face barriers in college. This thesis allows for greater research in the area of chronic illness in college.

Q&A Discussion

During the discussion, a question was raised by a participant whether any of the panelists were aware of whether universities have knowledge about disability inclusion criteria in hiring practices. Basch indicated that while she is not familiar with the universality of disability in hiring practices, it depends on the individual doing the interviewing and how much they understand and value disability.



Basch summarized that “people would only ask about disability if they cared about it.” Basch noted that when she has a say, she makes sure that whomever she hires is responsive to student needs. She also mentioned that it is a question of whether the individuals are utilizing these practices or not.

The panelists were then asked about what advice they would give to higher education professionals about how to be more intentional about ensuring that students feel more welcome and included throughout the accommodations process. Armstrong mentioned that there some people do not feel like they are “disabled enough.” There is a pervasive idea that someone “isn’t actually sick enough” to need accommodations. Armstrong said that it is important to understand that the current system is not built with disability in mind - some people are classified as “too disabled” and others are classified as “not disabled enough.”

Armstrong also described that there is a lot of professor pushback because they hold so

much power in the higher education setting. He acknowledged that it can be hard to go to a professor and be turned down even for an “easy” accommodation request, especially considering how often a letter of recommendation or extra credit is dependent upon a professor’s judgment.

"There is a pervasive idea that someone 'isn't actually sick enough' to need accommodations."

- Elijah Armstrong

Allegra mentioned that a key area of improvement is the collaboration and increased communication between offices, such as the Disability Resource Center and the Veteran Affairs Office. Namely, as Allegra pointed out, veteran students may never go to the disability office and may only go to the veteran’s office, so it is important to find commonalities and shared language to co-create and share materials with each other.

Basch discussed how the very first paragraph of a resource at her institution's Disability Resource Center includes language about power and privilege. She stated that other Disability Resource Offices should similarly address power and privilege, which can help open up conversations. Basch also highlighted that it is crucial for institutions to sustain support for these endeavors, and that it is difficult to work with these institutions if they don't have support.

“You wouldn't know what is in the environment until you are in the actual environment.”

- Richard Allegra

The next question posed to the panel was about how higher education can be more personalized to fit students with dynamic disabilities, instead of relying on a “one-size-fits-all” approach. Allegra discussed the

interactive process taken from Title 1 (employment) and that it should try to apply it to other titles. The interactive process talks about the environments that the person is in and looks at ways to address this rather than solidifying accommodations before a person enters higher education. Allegra said, “You wouldn't know what is in the environment until you are in the actual environment.”

Armstrong discussed the level of creativity that students go to to meet their own needs when institutions cannot. Students develop ways to solve issues - a lot of the challenge is that accommodation offices have seen one specific thing work for particular students and then latch onto that and are then hesitant to try something else.

Basch's advice was to listen to students for things that allow them to be successful. Basch added that she has not seen enough specialized staff. It is hard to be creative if you don't understand, so it is essential to ensure that “really great people” with expertise are hired.

People have a deep fund of understanding and knowledge about implicit bias and the social model of disability. If one has not deeply confronted one's own implicit bias of what happens if someone says they are disabled, but they don't meet my preconceived notions of what disability can look or act like, then that can get in my way of making human and tragic mistakes about accommodating people. Allegra says that a major missing component is the lack of peer communities and knowledge. He says that the peer knowledge that is organic among students is missing. He said that opportunities through DREAM and other institutions are very important for people to talk from and learn from each other's experiences.



One final question about providing appropriate accommodations while adhering to program requirements was then posed. Specifically, one participant asked for advice for higher education professionals who are trying to provide appropriate accommodations while also meeting the specific learning outcomes for a particular degree.

Basch pointed out that if there is an essential skill that appears to not be accommodated, the central question is why it cannot be accommodated. Basch states that higher education professionals should consider what the “essential task” truly is - for example, is it essential to the learning objectives for a student to complete a certain maneuver or task in a specific way? Basch advised students and higher education professionals alike to continue asking the question “Why?” as a way to creatively design alternative solutions and accommodations. For example, if a professor asks for a student to write 20 pages, it may be worth re-visiting the page limit and considering whether the “essential task” of the assignment is generating ideas, or whether it is answering the prompt in 20 pages.

Adding to Basch’s point, Armstrong discussed the fact that standards shifted immediately during the onset of the pandemic. So many disabled people were asking and pushing department heads to consider what exactly is necessary. Attendance policies became flexible and

asynchronous classes became a reality almost overnight. Armstrong urged people to consider the question, “If we absolutely had to change this, what is the other way we would approach this? “

Part Three: Accessibility and Inclusion Within Student Life

The third part of the Roundtable focused on accessibility and inclusion within student life. Two students as well as a former higher education professional shared their personal experiences and perspectives on accessibility and inclusion on campus for students with chronic medical conditions. Speakers included Nathan Burns, a third-year undergraduate student studying sociology at San Francisco State University; Lizzie Cremer, an undergraduate student studying biochemistry and disability studies at a small liberal arts college in a rural area of Missouri; and Gerry Altamirano, the former Assistant Dean and Director of the Disability Resource Center at the University of Florida. The following highlights key information from each presentation regarding the experiences of disabled students and their involvement in student life, as well as an analysis of the existing barriers within student affairs and strategies for change.

Nathan Burns (he/they): Participating in Campus Life as a Disabled Student

Our first speaker, Nathan Burns, is a current third-year undergraduate student completing a BA in Sociology at San Francisco State

University (SFSU). They currently serve as a Student Fellow at the Longmore Institute on Disability at SFSU and as the Communications Officer for Disability Rights, Education, Activism, and Mentorship (DREAM) at SFSU. They identify as queer, nonbinary, multiply disabled, and neurodiverse.

Burns shared that he became a student fellow at the Longmore Institute on Disability at SFSU in 2019. The Longmore Institute works to revolutionize social views through public education and scholarships and offers students with disabilities the opportunity to gain career skills while also showcasing disabled people's experiences and working to build a culture around disability. Burns explained that through their work with the Longmore Institute, they came to understand disability as a social identity rather than just a health issue. He recalls that as he began to explore his own identity he also started looking for ways to connect with other students.

Burns went on to describe their experience working with other students to establish DREAM SFSU as an official student organization. DREAM is a national organization geared by and for college students with disabilities. Burns noted that his campus had no history of a disabled student group outside of the disability resource center and that they chose to become a chapter of DREAM as a way of boosting visibility and increasing connections and resources available to them.



Burns explained that their biggest goal was to create a group that was by and for disabled students and that while the Disability Resource Center hosted groups for different types of students, they wanted more flexibility to be able to support students who may not have the opportunities and resources to be diagnosed and thus formally connected to the Disability Resource Center. They indicated that this would help to maximize their reach and build strong connections across campus.

Burns remarked that the group has faced some challenges with varied rates of attendance and retaining new members due to the COVID-19 Pandemic and the issue that many students still struggle to accept

disability as an identity. Yet, Burns noted that his group has still been able to establish a dedicated team of six to eight officers as well as several regular members that have attended every meeting since the group's inception. He went on to outline the successful strides the group has made in terms of campus relations such as publishing an open letter to their campus community to encourage the inclusion of disability in diversity efforts, meetings with their campus President, Vice President of Student Affairs and Enrollment Management, Associate Vice President of Equity & Community and Provost. They also detailed the group's plans for members to participate in a student success panel geared towards faculty members as well as plans to host an "intersectionality week" alongside the Queer and Trans Resource Center and a talk by disability activist Alice Wong.

Lizzie Cremer (she/they): Navigating College Life With a Chronic Medical Disability

Our second speaker, Lizzie Cremer, is an undergraduate student with multiple chronic illnesses. They are

studying biochemistry with a minor in disability studies and has plans to attend medical school starting in the fall. While completing their degree at a small liberal arts college in a rural area of Missouri, Cremer has been involved in several disability advocacy endeavors including co-founding a chronic illness support group and a neurodivergent advisory board.

Cremer recalled feeling a great deal of isolation during her freshman year of college. They explained that they did not want their illness to interfere with the way they were viewed by peers, so they kept their condition to themselves, even when flares led to multiple hospitalizations. This only led to increased feelings of isolation, exhaustion, and fear of what would happen if her illness progressed. Cremer went on to describe a pivotal moment that occurred while taking an Introduction to Disability Studies during which she saw a representation of invisible disability in a film. Cremer noted that before this, they struggled to identify as disabled and had not believed their physical symptoms to be severe enough.

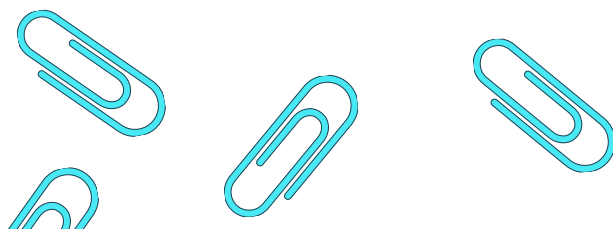
Cremer stated that after this moment, she began developing the self-advocacy skills and language to describe her experiences. They explained that as they started to openly share their experiences in class, they began to meet other disabled students and eventually formed a chronic illness support group. When recounting discussions within this group, Cremer recalls a collective realization that there was a greater need for advocacy on campus concerning disability. She also notes a shift in how the group viewed disability. In the beginning, the group viewed disability according to a medical model in which disability is a problem within an individual that should be fixed, but over time they began to view disability through a social-model lens in which it is the lack of accessibility imposed upon people with impairments by society.

When reflecting on what she and others have wished that people understood as far as what it's like living with a chronic illness, Cremer emphasized three dominant aspects of this experience. First, being ill is a full-time job.

Second, the lack of visibility for those with chronic medical disabilities only amplifies the isolation they already experience. Third, students with chronic conditions often feel forgotten in conversations regarding accessibility and inclusion. As campus groups are beginning to assess physical accessibility, this is where the discussion typically ends.

Cremer concluded her presentation with a summary of key takeaways and ways in which higher education professionals can be intentional when it comes to accessibility on campus:

- Adopt universal design principles
- Offer remote and recordings
- Let students know that they are valued and that their ability to access groups is of high importance
- Understand that many disabilities are dynamic
- Trust that disabled students know what they need best



Gerry Altamirano (he/him):

Colleges & Universities must Recognize Disability as a Valued Aspect of Diversity

Our third speaker, Gerry Altamirano, is the former Assistant Dean and Director of the Disability Resource Center at the University of Florida. He identifies as a first-generation, Mexican-American, queer cisman from a working-class family. Altamirano's social identities shape how he approaches diversity, equity, inclusion, and access work and his lived experience led him to explore a career trajectory interrogating social inequities and serving historically oppressed groups.

Altamirano began his presentation by emphasizing that universities must recognize disability in the way that they recognize other historically marginalized identities. Altamirano noted that while universities are giving more attention to the lack of inclusion and accessibility for disabled students in learning environments, the limited participation opportunities within student life are overlooked. He feels that it is truly the responsibility of administrators and higher education professionals to advance access

and inclusion in student life and student activities.

Altamirano went on to explain his recommended strategies for universities and higher education professionals:

- Use **Crip Theory** to unlearn internalized ableism and reimagine what student affairs and involvement look like
- Advocate for disability chair positions on student government and student activity boards
- Provide effective disability training for staff that centers on disability identity as an important facet of campus diversity
- Develop mechanisms for assessing barriers to participation for students with chronic medical disabilities.
- Hire and retain staff with chronic medical disabilities
- Shift from a disability accommodations/ services framework to a disability cultural center model to transform the experience for students on campus

Altamirano also maintained that it is up to students with disabilities to disrupt compulsory able-bodied spaces by showing up; resist oppression by being seen and demanding inclusion. In doing so, Altamirano explained that it is important to understand the systems operating on campus and be able to use them to your advantage. Altamirano gave examples such as understanding the process for creating clubs on campus, policies that may limit staff from creating clubs on behalf of students, how the university funds student organizations, and any resources a student organization may need to be successful.

Altamirano encouraged disabled students to run for student government and other campus leadership positions and to foster positive relationships with gatekeepers that may not be knowledgeable on how best to support students with chronic medical disabilities. Altamirano explained that some directors of student activities may not be aware of the true isolation that exists for students with chronic conditions, but that students can educate them and cultivate amicable relationships.

Altamirano noted that students must recognize that universities historically were not created for people from marginalized backgrounds and thus, students should not be afraid to create change through alternative means like filing a complaint or finding ways to leverage what the university cares about such as public relations and serving students of diverse groups when necessary.

Q&A Discussion

To begin the discussion, the speakers were first asked for their recommendations for students who want to get involved on campus and integrate their chronic medical disabilities within student life, but who do not have the bandwidth or resources to start a student organization. Cremer underlined the value of creating informal support spaces or possibly finding able-bodied allies to help take on some of the necessary tasks when starting a more formal group.

Burns indicated that just being able to openly discuss your experiences as a student with a

chronic medical disability without shame and bring disability into the conversations on campus can bring about awareness and understanding to other students and higher education professionals. Altamirano added to this by encouraging students to “show up and share who you are and be proud of who you are.” He went on to note that owning your own identity can often provide permission to others to do the same and that this can be a way to start building a community around you.

"Show up and share who you are and be proud of who you are."



- Gerry Altamirano

Altamirano was then asked if he could explain what a disability cultural center is and what that might look like on campus since the concept of a disability cultural center is still fairly new and unfamiliar to a lot of students and higher education professionals.

Altamirano explained that most of the disability centers or service offices that you see are designed to accommodate students because of the Americans with Disabilities Act (ADA) and that they are essentially disability compliance, designed to do the bare minimum to keep schools out of trouble. He further explained that these centers operate according to a medical-model framework in order to approve accommodations.

In contrast, Altamirano described a disability cultural center as being more like an LGBT+ or multicultural center. He explained that these centers embrace disability culture and identity, and operate under that same sort of relationship to academia where they utilize disability studies and Crip Theory to inform their practices and how they develop the identity of students to be one that celebrates who they are. Altamirano explained that in doing so, these centers perpetuate the understanding that there's nothing wrong with the individual but rather the way that these individuals are viewed and treated within society.

Burns then described the Longmore Institute where they work as being like a disability cultural center. He noted that the office has a library of books about disability open to all students and that they even host disability film festivals. Cremer also shared their perspective and explained what this currently looks like in rural areas. They described their school as being very “behind the times.” Cremer clarified that her school does not have a disability cultural center and while they do have a disability studies program, many students fall behind and end up dropping the minor. They also noted that their school’s disability office currently consists of only one person who runs the entire office.

While discussing important considerations when evaluating prospective schools or programs, Cremer noted that while researching potential medical schools, they would often start by emailing the school’s diversity office (or whatever office would be most appropriate) to ask if they could be connected with a disabled student. They described the responses as being very eye-opening as a lot of the schools were unable to do so.

Cremer said that this indicated to her that the school may not have made an effort to create an environment on campus where students felt comfortable disclosing their disability.



Altamirano stressed the importance of paying attention to the attitude or rhetoric that exists within a school's disability services office as this is going to permeate into their relationships with faculty. Altamirano noted that if a school’s disability service office only thinks about accommodations in a very reductive way then it is unlikely that they will be supporting, advocating for, or educating factually on a student’s behalf.

All the speakers acknowledged the understanding that not everyone will have the ability to pick and choose what college they want to attend for various reasons. Burns reiterated this point to emphasize the importance of the work that students are currently doing from within to challenge the system and make all campuses more inclusive for students in the future.

Part Four: Promoting a Campus Culture Embracing Students with Chronic Medical Disabilities

The fourth and final part of the Roundtable included personal and professional perspectives on how to promote a culture of understanding and support for students with chronic medical conditions, both by tackling common misconceptions about these students and by providing resources to students, faculty, and administrators for further learning and action.

Speakers included Syreeta Nolan, Co-Founder of Disabled in Higher Education on Twitter and Founder of JADE (Justice, Advocacy and Disability Education); Eiryn Griest Schwartzman, Co-Founder of COVID Safe Campus and a public health and disability justice advocate; and Alicia Wackerly-Painter, Director of Access and Student Support for Arizona State University Student Accessibility and Inclusive Learning Services.

The following proceedings include key insights about tangible steps for educators, student affairs professionals, and students to work together to create a world in which the higher education space embraces students with chronic medical disabilities.

Syreeta Nolan (she/her):

The first speaker, Syreeta Nolan, identifies as a Disabled Black bisexual Indigenous woman. Reading the Black feminist disability framework helped Nolan understand her intersecting identities, and as she experienced the challenges of navigating higher education, she spoke to the ideas of resilience and survival as a form of resistance, particularly for Disabled Black women.

As Nolan shared her wide range of advocacy experiences, from recently co-founding Black Disabled in Higher Education to serve as a Board Member for HealthAdvocateX, she emphasized that though she originally started to advocate out of necessity, rather than choice, she is grateful to be able to use the message of what she has gone through as a message of hope for others with similar life experiences.

Nolan pointed out that although the disability community is one of the largest minority groups, it is an identity that has been left out of Equity Diversity and Inclusion (EDI) initiatives. Sharing that “intersectionality is about fighting discrimination *within* discrimination” (Center for Intersectional Justice), Nolan pointed out that where there are instances of racism and homophobia, ableism is also an underlying factor - though it was oftentimes not recognized as such, because of the exclusion of the models of disability in our society.

“Intersectionality is about fighting discrimination *within* discrimination”

- Center for Intersectional Justice

Nolan went on to share that although higher education seems to primarily be based on the medical model of disability, which views disability solely as something that is diagnosed by a doctor and requires accommodations, we should be educators on what disability is within the social model: a culture, an identity, and a diverse community.

In this context, she also shared about the concept of disability pronouns and identity-first language. Nolan shared that her disability pronouns are “neurodivergent, dynamically disabled, invisibly disabled, and a disabled woman,” and that this is the language that she identifies with and prefers. Similarly, Nolan notes that it’s essential to consider how each student identifies, instead of making a blanket assumption that person-first language (for example, “student with autism”) is “better” or “more respectful.”



In fact, Nolan noted that members of the autistic community generally prefer the term “autistic person” (a type of identity-first language).

In Nolan’s words, what resilience looks like to her is “being exhausted, [facing] so many systemic barriers...and so much trauma, including medical trauma.” Nolan pointed out the fact that students are forced to deal with ableism alone, in part because ableism is not a word that is often used or confronted in higher education settings. Additionally, she shared that while resilience is generally talked about as an individual attribute of a disabled person, it also needs to be viewed as a contribution to addressing barriers to inclusion. These sentiments led Nolan to co-found Disabled in Higher Education. From their first campaign, Disabled in Higher Education Month in October 2021, they now have a community of over 10,300 people and have expanded to create the Black Disabled in Higher Education platform.

To illustrate Nolan’s call for disability justice, she shared a tale of two perspectives of Equity, Diversity, and Inclusion (EDI) as a marginalized student. Nolan illustrated that equality and equity are not the answer to serving the needs of disabled students, particularly if they do have multiple marginalized identities. Justice is a framework that can help create a world in which being disabled doesn’t automatically mean that you will be “othered” in higher education.



In practice, Nolan suggests that this disability justice framework in higher education can include the following:

- Supporting disability pronouns in a similar way that gender pronouns are supported
- Supporting neurodivergent students, both formally and self-diagnosed, to reduce the impact of health inequities, such as barriers to healthcare
- Supporting disability studies programs, disability mentoring programs, and discussing ableism in a similar way to racism
- Creating safe spaces for disabled students, such as Disability Community Centers on college campuses
- Exploring the ableism in many fields for disabled students, researchers, faculty, and staff
- Taking the time to talk to the Disability community about the barriers that they have faced, such as in the classroom and working at a lab
- Include disability in Diversity, Equity, and Inclusion efforts
- Be willing to learn about the scope of disability history and ableism

Eiryn Griest Schwartzman (they/them)

The second speaker, Eiryn Griest Schwartzman. With a B.A. in Public Health and a minor in Sociology, they are a public health and disability justice advocate and also the Co-Founder of COVID Safe Campus. Having been diagnosed with several chronic illnesses at age fourteen, Griest Schwartzman experienced firsthand the notion that disabled students “don’t belong” in academia. They shared that as a junior in high school, their school told them that they were a drain on resources and cut off their access to home teaching services, leading Griest Schwartzman to drop out of high school and go directly to college at age sixteen.

Griest Schwartzman emphasized that the administrative barriers and injustices they faced at their community college, and later at their university, made this experience unsupportive and isolating, pointing out that having supportive people on campus does not equate to having a supportive campus.

Describing self-advocacy for disabled students in higher education as “exhausting, discouraging, lonely, confusing, and overwhelming at best,” Griest Schwartzman shared that the trauma of having to fight for their rights and endure systemic ableism was in some ways more degenerative than their disease itself. Given that this advocacy can be emotionally and physically draining, they suggested that community organizing and advocacy efforts, with disabled students and allies alike, can buffer the impact of having to engage in this alone.

Leading with the premise of “If the campus culture won’t accept you, build your own,” Griest Schwartzman illustrated the ways in which this informal disability mentorship can manifest, including helping one another work through the nerve-wracking process of asking professors for extensions and passing down “disabled wisdom” to other disabled students who may be newer to navigating this space.

In regards to shifting towards collective access and putting disability justice into practice, Griest Schwartzman believes that we need to:

- Normalize prioritizing health over academia, including the need for taking breaks and making space for mental health
- Promote the work of disability justice scholars and advocates, not only to make disabled folks feel seen, but also to build solidarity and shared understanding
- Design virtual and in-person spaces, from classrooms to campus events, with collective access in mind, without anyone having to ask for these accommodations
- Grant accommodations without documentation or diagnosis, given the ableist, racist, and classist barriers that can exist within the administrative process
- Explicitly name the ways in which structural oppressions impact students every day, including the intersection of certain identities and the mass trauma of the COVID-19 pandemic

Griest Schwartzman went on to share that in order to truly shift our campus culture, we also need to recognize the ableism in campus health programming, given that this programming is typically designed with the average, “healthy” young adult in mind. Moreover, Griest Schwartzman pointed out that the programming that promotes health and wellness on college campuses is often centered around “avoiding the consequences of being disabled or chronically ill” through engaging in physical activity, getting more sleep, eating healthy, etc, while failing to recognize that these lifestyle changes are unattainable and inaccessible for disabled students and frames our experiences in a negative light. They mentioned that health education, from sex education to drug and alcohol education and ‘lifestyle’ changes, must have a component of disability solidarity in order to truly include students with chronic medical disabilities.

Finally, Griest Schwartzman shared their mission and work through COVID Safe Campus (CSC), a disability-led community organizing project advocating for improved COVID safety measures, accessibility, and disability inclusion in academic institutions.

They aim to highlight the unmet needs of high-risk students, staff, and faculty through advocacy resources and training, research reports, and virtual support spaces. Ultimately, Griest Schwartzman points out that many of the strategies being implemented by CSC are not exclusive to COVID; rather, they can be used as a framework for others to organize around any disability justice issue on campus.

Alicia Wackerly-Painter (she/her)

The third and final speaker for this discussion, Alicia Wackerly-Painter, who serves as the Director of Access and Student Support for Arizona State University (ASU) Student Accessibility and Inclusive Learning Services, overseeing the accommodations and support process for disabled students. She is currently also working on her doctoral dissertation on the experiences of students with invisible and hidden disabilities on college campuses.

Wackerly-Painter shared that self-determination is a key component of the experiences of disabled students, as she believes that these students

understand themselves and their disabilities best and are thus best equipped to be in the driver's seat of their own educational and professional journeys. In particular, she says, students with invisible disabilities do have the unique opportunity to decide how much they want to disclose about their particular disability and the impacts on their life. Wackerly-Painter emphasized that the campus culture around these students is a major influencing factor on whether or not these students feel comfortable and supported in disclosing their disability identity, which drives her work at ASU.

Access Zone is one such initiative, which was grounded in disability studies research and was designed to educate the ASU campus community about disability and what it can look like beyond the medical model. By sharing what disability can actually mean and look like in students' lives, beyond the need for accommodations, Wackerly-Painter and her team hope to redefine others' perspectives of disability, ultimately creating a more supportive environment for students with disabilities.

She shared that this perspective also grounds the faculty and staff

trainings that ASU Student Accessibility and Inclusive Learning Services facilitate, emphasizing the importance of customization for each of these trainings in order for faculty to truly understand what potential challenges or experiences that disabled students may face in their department or a specific program, and how to change that to make it a more supportive environment. Wackerly-Painter also noted that she and her team have been hosting Lunch and Learn events, for students and faculty alike, that address various aspects of the disability experience.

She believes that the more we provide an opportunity for individuals to learn and talk about disability, the better the community itself will be for these students. This perspective has driven the new programs that are being created through ASU Student Accessibility and Inclusive Learning Services, including peer-to-peer mentoring programs, providing an opportunity for disabled students to support one another, and a disability studies-based class that helps students with disabilities contextualize their own disability within their own life and campus, including recognizing ableism and building self-determination.

Wackerly-Painter also shared that she is the advisor to the Disability Advocacy and Awareness Board, which is currently led by ASU's undergraduate student government, and the Accessibility Coalition, a collective of student representatives from the various disability-related organizations on campus. She encourages students to look for similar organizations on their college campuses, because although not every campus may have a Disability Cultural Center, they may have other opportunities (such as the Accessibility Coalition) that foster disability community-building.

Wackerly-Painter acknowledged that there are many disabled students who have had negative experiences with Disability Services at their various universities. She shared that for Disability Services to be able to move beyond the medical model of disability, it's important that disability offices are intentional about meeting with every student, regardless of disability documentation status and about providing campus education that is centered around disability experiences rather than solely the accommodations process.

Q&A Discussion

When Wackerly-Painter was asked what advice she would give to higher education professionals who are looking to create something similar, beyond the basic "checklist" of accommodations, she said that the biggest thing that higher education professionals in disability services need to do is to first recognize the background that they are coming from. In Wackerly-Painter's own experience as someone coming from a rehabilitation background, she did not realize that she was more primed to focus on the medical model of disability and had less exposure to other models. As she emphasized, "If we think we're doing everything right, we're never going to be able to do things differently," which highlights the importance of each person critically considering which types of ableism they may be (intentionally or unintentionally) upholding.

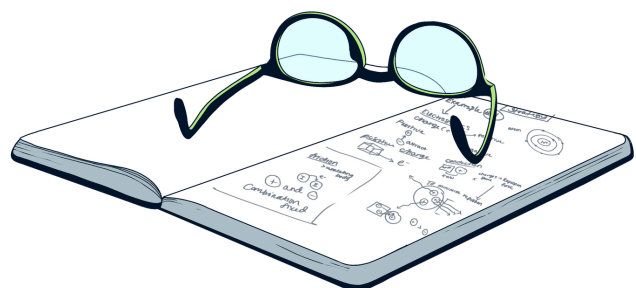
Secondly, Wackerly-Painter noted that people working in disability services are often looked to on their campuses as experts in that particular field.

Because of this, she believes it's the responsibility of these individuals to train their community in a way that is not just performative; rather, they should work within their campus to go beyond simply offering accommodations, and to think about what disability and community mean for their students. Ultimately, this can help build these students up and make sure that they feel supported, which is an essential goal of higher education professionals in this space.

Wackerly-Painter was then asked about her thoughts regarding the use of a standard statement on disability and accommodations in class syllabi and the way in which professors address this within their classes. She discussed a research study that showed that students are more comfortable with (and more likely to stay in the class of) professors who discuss the syllabus beyond the standard template language. Moreover, Wackerly-Painter said it is the responsibility of Disability Services professionals to equip professors not just with the language to put in the syllabus, but also with appropriate ways to discuss this and refer students as necessary.

When Nolan and Griest Schwartzman were asked about their perspectives on how to include disabled students, while also recognizing the impact that this can have on students, Nolan emphasized the fact that "Nothing about us without us" means that disabled students should be there when crafting the disability/accommodations statement in class syllabi - and to make sure that classes all have syllabi, so that disabled students can know what to expect.

Moreover, she stated that it's important for marginalized communities on campus, such as the Black Student Association and LGBTQ+ Center, to collaborate with disabled students, to ensure that the disability community is being recognized, accommodated, and spoken to.

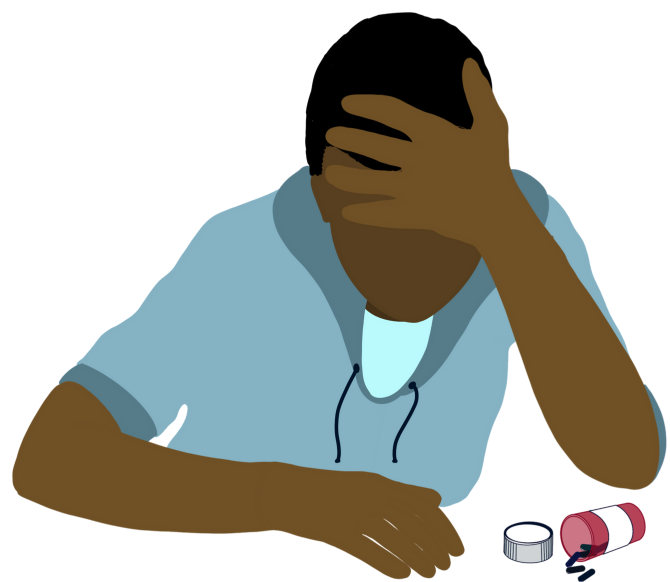


Nolan pointed out that within every marginalized community, there are generally higher incidences of disability, highlighting the importance of deconstructing the ableism embedded within various cultures. Nolan encourages these communities to lean into other ways that the body and mind can exist, and to learn from that to better include the intersection of disability with other varied identities.

Griest Schwartzman expanded on this to point out that **disability spaces have been predominantly white**, and there are several **barriers to obtaining diagnoses and documentation for accommodations**, which are more prevalent in underrepresented and underserved communities. Specifically, Griest Schwartzman pointed out that certain students have been excluded from obtaining disability documentation, due to **systemic racism, discrimination, white supremacy**, financial and transportation barriers, and disability itself. They emphasized the importance of being mindful of this when considering what the documentation process is for each

Disability Office and suggested that removing or reforming the disability documentation process itself can be one way to alleviate the inherent power dynamic between disabled students and accommodations offices/universities.

On the topic of representation in Disability Office staff, Griest Schwartzman also noted that having a Disability Office that is led by and comprised of disabled staff members can foster a more understanding environment for the disabled students, while also supporting the careers of disabled people.



Overall Discussion & Themes

Throughout the Roundtable, recurring themes emerged that we felt were crucial to highlight in order to provide additional context as multiple speakers shared their personal and professional experiences relating to the topic. As disabled authors of this proceedings document, many of the themes resonated deeply and are extensions of our own experiences navigating higher education. While we are unable to cover all themes we felt were critical to emphasize, below are a few we feel are important to highlight from the Roundtable.

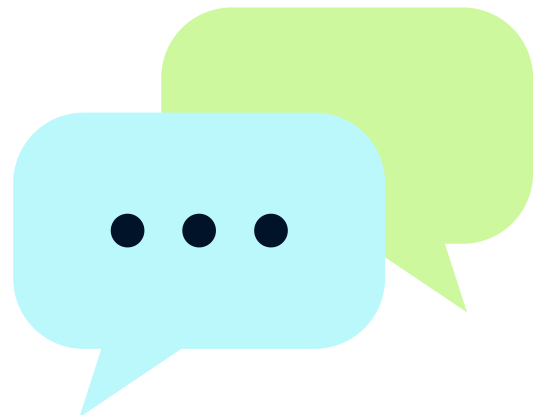
Recurring themes:

- Language
- Psychosocial Impacts: Isolation, Trauma, and Toxic Resilience
- Mentorship
- Disability Models, Culture, and Identity
- Power Dynamics
- Allyship over Awareness

Language

Language is critical in the development of disability as both a culture and identity. Unfortunately, societal misconceptions around the term disability can have damaging psycho-cultural overtones (Andrews et al., 2019). Society often seems to readily push the label of resiliency while at the same time evading the use of the word 'disabled' or 'disability,' and professing terms such as 'handicapable' or 'differently abled' to be more appropriate.

This is especially true within higher education spaces which, as Syreeta Nolan explained, “requires a toxic level of resilience” on the part of disabled students in order to succeed.



Unlike other forms of discrimination, ableism is rarely acknowledged or discussed. It is not common practice to ask those with disabilities how they prefer to be identified (“disability pronouns”) in the same way people are asked about their preferred gender pronouns. Moreover, as several speakers mentioned, people who outwardly identify as disabled are often blatantly discouraged from doing so. This attempt, whether intentional or not, to eradicate disability from our collective vocabulary only acts to further solidify the notion that disability is an inherently negative term synonymous with weakness and in direct contrast to the notion of resilience that has been so ardently deified.

We have found, from our own experiences and discussions with other young adult patients outside of our organization, that for many, being able to use terms such as ‘disabled’ and ‘patient’ without shame is extremely useful in communicating and engaging with our community and the various systems we face as young adults. Unfortunately, the stigma and misconceptions surrounding these terms make it difficult for many individuals to feel confident in

identifying themselves in this way, even if it leads to further isolation and lack of support for their needs.

In order to create an environment that is truly inclusive and empowers students with chronic medical disabilities, we must begin to view disability as a fundamental arm of diversity, and no longer as a shameful or limiting concept.

Psychosocial Impacts: Isolation, Trauma, & Toxic Resilience

The impact of chronic medical conditions transcends the medical space – the psychosocial toll of navigating academic spaces with a disability cannot be ignored. While young adulthood is often described as being the “prime” of one’s life, this is not typically the case for young adults living with chronic and rare conditions who are regularly confronted by ongoing pain, sacrifice, and decreased quality of life. However, there are major contributing factors to this reality that are not a direct result of the individual’s condition.

Speakers Lizzie Cremer and Eiryn Griest Schwartzman both discussed the intense isolation that is a common theme experienced among students with chronic medical disabilities. Current systemic barriers and a lack of visibility within institutions of higher education create environments that amplify feelings of isolation, shame, and even a reluctance to identify as disabled. These environments disempower disabled students by covertly inhibiting the ability to engage with peers and thrive overall within the higher education system. As Griest Schwartzman pointed out, the constant need to advocate for oneself in these spaces can be an exhausting, frustrating, and traumatic experience - which, in turn, leaves these students with less time and energy to socialize and to pursue academic, career-oriented, and other endeavors. Moreover, given these unique experiences, disabled students may not relate to their peers in the same way, further compounding feelings of isolation.

As mentioned above, society, and institutions of higher education in particular, aggressively push the label of resiliency onto disabled

students without adequately acknowledging the challenges these students face within this system. Again, as Nolan so perfectly stated, it takes a “toxic level of resilience” for disabled students to succeed in higher education and if they are able to, it often comes at a cost to both their physical and mental health. This is made worse by the emphasis on “wellness” and forms of destructive, and often false, positivity that are currently so pervasive on college campuses. As a result, students with chronic medical disabilities often feel as though their experiences are minimized. Furthermore, students have reported feeling a tremendous amount of shame and even guilt for not meeting the expectations of health, resilience, and inspiration set by those around them which in turn plays into this vicious cycle that only intensifies feelings of isolation and mental exhaustion.



Mentorship

Given the isolation that students with chronic medical disabilities often experience, it is crucial for these students to have mentorship and peer support opportunities to foster community. Sharing one's lived experiences in both informal and formal ways can be a powerful way of building an accepting, welcoming space. Cremer and Nathan Burns both shared their experiences co-founding and leading student organizations on their respective college campuses, as a way of creating a space where disabled students can band together in solidarity and be in community with one another, sharing in each other's experiences and helping one another navigate campus, disability, and all that this brings.



Creating community and mentorship for disabled students does not only need to be done through a college or university. Speaker Nolan shared her experience co-founding Disabled in Higher Education, a global online community that seeks to empower and support disabled students through their academic journeys.

Similarly, Generation Patient launched a Student Support Network in September 2020, which was originally founded with the intent of providing a safe space for students from across the nation to virtually connect with one another during the COVID-19 pandemic, particularly as many students were away from campus life. Though many college campuses have since opened up, the need for the Support Network remained, as students had expressed a desire for a community that exists beyond their individual universities - not only to be able to connect with similar students from across the nation but also to share diverse experiences and ideas through all aspects of navigating higher education with a chronic medical disability.

While setting up a formalized mentorship program or other organization can be powerful, it is not the only way of fostering peer mentorship. Griest Schwartzman highlighted the importance of informal peer networks, sharing that disabled wisdom—something that all disabled students have—can and should be passed down. They have seen this firsthand, as they have worked to help other disabled students on their campus write emails to professors to grant extensions, meet with administration to share community concerns, and share tips on navigating ableism through the school experiences. The exchange of this wisdom and mutual aid rooted in lived experience can help build community and access from the ground up.

Disability Models, Culture, & Identity

The lens through which we view disability directly impacts our societal rhetoric and treatment of disabled individuals. Yet, differing models of disability are rarely discussed.

Many of our speakers touched on two distinct models that have been created to exemplify how society views disabilities: the medical model and the social model. These models provide a framework for how people perceive and thus engage with those with disabilities.

The medical model frames disability as a defect within an individual, a problem that should be fixed, or will otherwise result in an inherent loss of autonomy and quality of life. The focus of this model is on the individual's impairment and how this excludes them from mainstream society which inadvertently minimizes and devalues disability. In higher education specifically, there is a propensity towards the medical model, which is used by institutions to distinguish whether or not a student is deserving of accommodations necessary for their participation, so long as those accommodations are deemed "*reasonable*," the definition of which varies greatly across different schools, departments, and individual faculty and administrators.

As pointed out by both Nolan and Griest Schwartzman, subsequent attitudes that result from the pervasive use of this model not only create a more hostile environment for students with chronic medical disabilities, but also dissuade the formation of an identity and culture around disability.

As previously discussed, institutions within society often paint a rigid and misleading portrait of disability, which, combined with this emphasis on the medical model, regularly results in confusion and false conceptions of disability for students with chronic and rare illnesses, many of whom live with conditions that are dynamic or non-apparent. As Cremer noted, during their freshman year of college, they did not feel they were “disabled enough” to seek support and accommodations from disabled student services, even after their condition resulted in several hospitalizations. Unfortunately, this is an all-too-common scenario wherein students will refrain from identifying as disabled and seeking support for their needs at a cost to their physical and mental health as well as their education.

In contrast, the social model argues that the issue is not the individual’s “impairment,” but rather societal

barriers that inhibit the person’s ability to participate fully. This model highlights discrimination and indifference within communities and institutions and reconstructs disability as a strength to be embraced and an identity around which students can form a collective culture, based on their shared experiences. Given this, as Nolan pointed out, the social model of disability is generally more conducive to using identity-first language and to being intentional about each person’s “disability pronouns” – or in other words, how the person would like to be referred to in reference to their disability experiences.

While the medical model does serve its own purpose, incorporating a social framework within institutions of higher education can help professionals and support staff better understand the holistic experience that students with chronic medical disabilities face. Namely, students’ experiences of their conditions are not only defined by their symptoms or medications, but also heavily shaped by their social environment, including an understanding (or lack thereof) of the psychosocial impacts of their disability by their peers, professors, and disability support staff.

Power Dynamics

Within disability services, there are often power dynamics between disability counselors and students. A notable article entitled “[Helping, Serving, Fixing](#)” describes the value of serving as equals rather than “helping” or “fixing.” In the context of chronic medical disability, this would entail a focus on helping and fixing someone’s ‘functionality’ without recognizing the wholeness of the person. In contrast, serving is a catalyst for healing which allows for a more mutual connection between the disability counselor and student. In this context, disability counselors often try to “help” or “fix” the immediate “accommodation fixes” rather than seeking to understand and serve the whole student.

During Basch’s presentation, she discussed how open she was about receiving accommodations as an adult. While this might have been a small part of Basch’s presentation, this was a critical moment in breaking the power dynamic and creating a safe environment to allow others to disclose their own disability.

While no one should ever feel obligated to disclose, this should be noted as invaluable in making sure students feel invited and encouraged to share their disability identity to receive accommodations. Basch also shared that at the top of the accommodation request forms she designed, there is language that specifically recognizes the power and privilege that inherently exists in these situations - and this acknowledgment can be an important step in breaking down these barriers.

Further, Basch pointed out that many people who work in disability offices don’t have expertise or knowledge of disability culture, and this, in turn, can pose barriers to individualizing services for disabled students. Speaker Gerry Altamirano also suggested that disability offices often treat student accommodations like a checklist. The bare minimum is often done and gatekeeping occurs for individuals not only in disability offices but also in student life programming such as within student government.

We believe that power dynamics play a role in students feeling comfortable with or open about accommodations. It is one step to simply tell students to ask for accommodations, but it is different when students have to make the ask. Armstrong also mentioned that professors and teachers hold so much power in being able to assign grades and extra credit, and this fact can often be a barrier to asking for accommodations. It takes a champion within large institutions to advocate for students and not automatically align with the institution's best interests. Basch's approach to disclosing her own accommodations is powerful in inviting students to do so themselves.

To Basch's point and others in the Roundtable, what if disability services did so much more than simply check all the boxes and fulfill the bare minimum required for the student to stay in higher education? As per Altamarino, disability centers should be reimaged to create space for the disabled student beyond solely accommodations and rather, recognizing the individual and their whole lives beyond the classroom. Power dynamics are pervasive within higher education, and it is up to all stakeholders to dismantle these and

create more accessible spaces for disabled students to thrive and participate in all aspects of student life

Allyship Over Awareness

Allyship over awareness is another critical theme. While awareness is important in creating the initial step of recognition, awareness without accompanying action is simply a passive form of understanding. In contrast, allyship promotes actionable ways to surpass the surface level of understanding and to take steps to increase education or advocacy.

Both Basch and Wackerly-Painter provided examples of creating disability training for professors and students, which can be a more active way to learn about disability identity and culture. As it pertains to disability education, there must be a better understanding of what disability entails and the diversity that exists within disability. Allegra also alluded to the need for campus centers to more proactively communicate with one another to find and ensure disabled students have the accommodations they need.

The theme of allyship over awareness is important because ‘awareness days’ can only do so much to move the needle toward increased acceptance and inclusion. Wackerly-Painter described creating more understanding about disability beyond accommodations in a campus environment. She facilitates events that promote understanding of disability identity. This is important in recognizing disability pride and both the value and power of shared disability experiences.

Wackerly-Painter uses lunch-and-learns to promote allyship by way of

discussion and actively including professors as part of the discussion. These lunch-and-learns provide a space for students and faculty alike to come together to discuss various aspects of disability identity. Wackerly-Painter alluded to how important it is for professors to understand the disability in context to the student, rather than solely having “awareness” about the disability. This personalization of living with disability is invaluable in taking the next step toward providing appropriate accommodations and an inclusive learning environment.

Recommendations

Given the findings of this Roundtable on Chronic Medical Disabilities in Higher Education, we at Generation Patient have the following recommendations for students, allies, student affairs professionals, and higher education institutions.

Increased creation of and support for disability-specific initiatives on college and university campuses:

- Campuses should fund and provide resources for student-led disability organizations, Disability Town Halls, and similar programs
- Campuses should consider creating and funding a Disability Cultural Center

Recognition and celebration of disability as a type of diversity, and thus as a crucial part of diversity programming and Equity, Diversity, and Inclusion efforts

- ▶ College and University Admissions Offices can include disability within their campus recruitment videos, such as featuring disability-centric programming
- ▶ The University's Office of Diversity, Equity, and Inclusion (or similar entity) can formally recognize disability as a form of diversity and appropriately fund and incorporate disability-specific programming

Education of medical professionals, both at campus health centers and in local clinics, about the accommodations processes and options for disabled students

- ▶ Given the role of clinicians in existing accommodations documentation processes, clinicians should be made aware of what accommodations exist for students
- ▶ Campus accommodation/accessibility offices can facilitate this by providing specific guidance for clinicians to understand the accommodations available to students, so they can help ensure their patients get the support that they need.

Increased peer support for disabled students

- ▶ Through our work at Generation Patient, what we have always known but what has been re-emphasized is that peer support should never be an afterthought, rather it should be a core intervention used within high education spaces to support students with chronic medical disabilities.

More research on the experiences of disabled students in higher education to further push necessary advocacy

- ▶ Specifically, there is a lack of research surrounding the experiences of students with chronic medical disabilities.

Increasing staff members who identify as disabled themselves and who have experience working with disability

- ▶ Lived experience is invaluable in working with disabled students.

Increased education for university staff and administrators regarding chronic medical disabilities and the unique challenges such as:

- Understanding dynamic disabilities, the unpredictability and continuously fluctuating severity of such conditions, and how higher education can be more personalized to fit students with dynamic disabilities, instead of relying on a “one-size-fits-all” approach.
- Recognizing the debilitating nature of symptoms like chronic fatigue as well as the psychosocial manifestations of chronic conditions and the importance of interventions such as peer support for these students.

Promotion of disability on-campus education by:

- Incorporating a social model of disability and emphasizing allyship over awareness.
- Awareness that disability can take many forms, including both visible and non-apparent disabilities, neurodivergent, and dynamic disabilities.
- Recognizing the need for accommodations vs. creating a culture of disability.

Transitions in the framework through which we view disability, looking at disability as an identity and through a cultural/ social lens:

- Establishing a culture and community around disability on campus
- Rather than encouraging “person-first” or only “identity-first” language, using the concept of ‘disability pronouns’ by asking students what they prefer. This is particularly useful to implement in ‘Inclusive Language Guides’ and similar resources that schools may create.

Students with chronic medical disabilities face numerous high costs. We recommend systematic changes to remove financial barriers associated with access to higher education for disabled students

- Investigate financial barriers
- Lower costs associated with navigating life with medical conditions. For example, many students with chronic conditions are on high-cost biologics for a lifetime, so it is imperative to remove financial burdens associated with prescription medications, a basic human need. Easing the financial burden inevitably removes one of the barriers to accessing higher education.

- Increase scholarship opportunities for disabled students.

Increased funding for disability-led higher education advocacy

- Many disabled people are tasked with advocating without compensation. The funding for disability advocacy is already very limited, but even more so for students and organizations engaging in disability advocacy. More foundation funding for students with chronic medical disabilities could create meaningful and sustainable change.

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