# Binghamton University Students with Disabilities'

# **Needs and Perceptions of Disability Services**

Meegs Longacre and Elaina Bonora

Human Rights Capstone

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#### Overview

In this study, we reviewed national and campus policies and laws centered on supporting students with disabilities, collected students' perception of these services, and explored what disabled students felt they need to succeed at Binghamton University. We interviewed individual students with disabilities, two student advocacy and social groups centered on disability (the Neurodivergent Club and the Disabled Student Union), the director of the Services for Students with Disabilities (SSD) office (Dr. Christen Szymanski), and a Student Affairs Administration faculty (Dr. John Zilvinskis) who identifies as a disabled scholar and researches students with disabilities. We also attended Binghamton University's Disability Research Symposium— a campus event where faculty, staff, and students discussed research on the disability community. We identified four related themes across these interviews and experiences:

- 1. Students are aware of laws, but have mixed reviews and engagement with the SSD office and typically avoid the SSD office due to stigma, concerns about accommodations, and issues with documentation;
- 2. Students recognize there is some privilege in having a diagnosis, and that a student's intersecting identities can impact their access to a diagnosis. As a result, students want self-diagnosis to have more validity;
- 3. Students feel a lack of social support and specifically seek social support from other disabled people;
- 4. Interviewees emphasized the importance of the tenet "nothing about us without us" for the disability community and research on the disability community.

## Researchers' Positionality

The researchers are students at Binghamton University. Meegs Longacre is a white, disabled student who does not use disability services from Binghamton University. They are a graduate student in the double degree Master of Social Work and Master of Science in Student Affairs Administration programs. They are researching this report as a graduate intern with the Human Rights Institute working under Professor Moore. Elaina Bonora is a senior majoring in English and minoring in Human Rights. She is currently working under Professor Moore in a Human Rights reflective capstone course. She receives academic and housing accommodations through the SSD.

#### A Note on Language

There is discussion around how to refer to the disabled community, and the language used on this topic is important. Some argue person-first language—for example saying "people with disabilities" or "students with disabilities"— is the more appropriate way to refer to people, while others, typically from the disabled community, argue that this separates them from their disability. Instead, they prefer to use "identity-first language," such as "disabled students/people." This is similar to the conversation around referring to someone as an "autistic person" as opposed to "someone who has autism." Throughout this paper we will alternate between the different ways to talk on this topic, and we will reflect the language that the individuals and groups being interviewed used. We also think it's important to note that individual's disability status can change at any point, and being able-bodied can be a temporary condition.

## **Background**

According to the US Department of Education, some of the laws that protect students with disabilities are Section 504 and Title II of the American with Disabilities Act (ADA) (2023). Section 504 prohibits an entity that receives federal financial assistance from discriminating against persons with disabilities. Title II of the ADA prohibits state and local governments from discriminating against persons with disabilities, and this includes public colleges and universities. When these policies refer to persons with disabilities, they mean any person with a physical or mental impairment that impacts their life on a substantial level (2023). According to Dr. Szymanski, Director of Binghamton University's Services for Students with Disabilities office, accommodations do have limits though, they must be deemed "reasonable" and not "fundamentally alter" the education or program (2023). If they are unreasonable or if they do fundamentally alter the program, accommodations can be denied without it violating any rights. An example of an accommodation that would fundamentally alter a program would be a Social Work student wanting an accommodation that allowed them to be exempt from the social work field placement due to their disability. The field placement is a fundamental part of the social work education and cannot be skipped without fundamentally altering the education experience so this could be declined. Instead, the office, department, and student might work together to determine was accommodations could be implemented at the field placement so the student can still engage with the education but also have support for their disability. Binghamton University as a public university and part of the SUNY system is required to uphold these policies so students with disabilities have an equal opportunity to get an education. Binghamton University's main resource for students with disabilities is the Services for Students with Disabilities (SSD) office.

According to the SSD website, the mission of SSD is to promote and facilitate: the educational and personal development of Binghamton University students with disabilities; the enhancement of the University's architectural and program accessibility; and the promotion of a

campus culture characterized by attitudes of caring, respect and inclusion (2023). Accordingly, the office states they serve a multidimensional role as service provider, educator, and advocate. Their operational philosophy is based firmly on the belief that the individuals served are students first and that their disabilities are secondary. The office consists of a director, an assistant director, three disability service specialists, a graduate assistant, and office assistant, and a few undergraduate student staff. These are only about 12 people working in this office, and they support over 1600 students. In a presentation Dr. Szymanski (2023) gave to the Master of Social Work department, she stated that approximately 1 in 12 students at Binghamton University are register with the SSD office. There are over 500 students registered with ADHD, about 250 registered with learning disabilities, nearly 300 students with chronic health conditions, and nearly 700 students with mental health conditions. All of these students have gone through the process of disclosing to the SSD office.

There is a five stage process to get accommodations: first, the student needs to initiate a request and self-identify to the office; second, they need to provide medical or physiological documentation; third, they review their current and ongoing challenges related to their disability; fourth, the office conducts a complete a comprehensive intake that outlines how the student's disability impacts their life; fifth, accommodations are selected with the student to mediate the disability and ensure the student has an even playing field to learn (Szymanski 2023). Some common accommodations that students receive are extended time on tests, a note taker or audio recorder, and reduced distracted learning or the ability to take a test in a less stimulating environment. There are lots of other accommodations, too, such as climate control, access supports to get around campus, fair housing act, no scantron testing, increased response time, preregistration, and all-format tests. There are also services like referrals to the counseling center, tutoring, academic advising, and other services that would not directly count as accommodations.

Finally, as mentioned before, services do need to be reasonable and not fundamentally alter the educational program, so the office does need to consider this before approving or declining any accommodation. The office is the only one who can determine this; for instance, a faculty member can not deem something unreasonable or state something fundamentally alters their class. The faculty would need to refer to the office with their concern.

Despite these policies and offices, according to the National Center for Education Statistic, only a third of students with disabilities reported their disability to their universities, and sixty-one percent of students who did report a disability received university services (2022). Despite these supports, students sometimes avoid these services and avoid reporting their disability due to common issues and concerns. These include believing or experiencing instructors having lower expectations of them, being treated differently than their non-disabled peers, mental health struggles, advisors' lack of knowledge on supporting students with disabilities, lack of quality support services, and social stigmas (Hong 2015). Considering these common concerns, students from institutions across the country have expressed lack of access to accessibility services, lack of interest in services, and lack of community as key barriers to support. In response to these common issues, students across college campuses are developing Disabled Student Unions to meet their needs (Carrasco 2023).

At Binghamton University, a Disabled Student Union was established this past year by disabled students (Wilner 2022). The goal is to bring awareness about disabilities and provide support to students. The DSU informs members of services, discusses accessibility on campus, and works with the university on ways it can improve support for disabled students. They explained that students on campus have expressed struggles with the SSD office and Binghamton University policies, so they founded this group as a place to discuss experiences and possible solutions.

Binghamton University's independent student-run newspaper, the *Pipe Dream*, details the struggles a student experienced with trying to get an emotional-support animal for her emotional health (Bilello 2017). She expressed frustrations with working with the SSD office, obtaining the needed documentation, and feeling stigmatized throughout the process. Our study explores below how students with disabilities and student groups have experienced their time on campus.

# Methodology

For the purpose of this report, we are exploring students' perception of the support Binghamton University provides and the policies and resources at Binghamton University for students with disabilities. To explore this, in Spring 2023, we interviewed the director of the SSD office— Dr. Christen Szymanski (summarized in appendix A); individual student interviews (summarized in Appendix B); the Neurodivergent Club (summarized in appendix C); the Disabled Student Union (summarized in Appendix D); Dr. John Zilvinskis— a Binghamton University student affairs administration associate professor and disabled scholar who researches and teaches a class on best practices on supporting students with disabilities (summarized in Appendix E); and we attended the Disability Research Symposium (summarized in Appendix F). This was an event on May 5<sup>th</sup> 2023 where faculty spoke on the research they do on individuals with disabilities, Dr. Szymanski briefly spoke, and Student Affairs Administration graduate students presented their research on best practices with disabled students as part of a student affairs course related to working with disabilities. This was also a networking opportunity for students, staff, and faculty with disabilities and allies to meet one another.

All the students interviewed have disabilities and varying levels of engagement with the SSD office. Interviews include perspectives from students who have disabilities and receive services, students who have disabilities but don't receive service, students who receive services but

do not use their accommodations for varying reasons discussed throughout this report, and students who do not have an official diagnosis so do not receive services. The vast majority interviewed were reporting on their experience with learning disabilities and mental health issues; a limited number of students with physical disabilities were interviewed. We also researched laws and policies in New York, the SUNY system, Binghamton University, and the Binghamton University SSD office.

#### **Discussion**

We will discuss in detail the four common themes below:

- 1. Students are aware of laws, but have mixed reviews and engagement with the SSD office and typically avoid the SSD office due to stigma, concerns about accommodations, and issues with documentation;
- 2. Students recognize there is some privilege in having a diagnosis, and that a students' intersecting identities can impact their access to a diagnosis. As a result students want self-diagnosis to have more validity;
- 3. Students feel a lack of social support, and specifically seek social support from other disabled people;
- 4. The importance of the tenet of "nothing about us without us" within the disability community.
- Theme 1: Students are aware of laws, but have mixed reviews and engagement with the SSD office and typically avoid the SSD office due to stigma, concerns about accommodations, and documentation.

The first theme that became clear was that students are aware there are laws and policies that protect their rights, but students have mixed reviews of the SSD office and varying levels of engagement. In general, students avoid the SSD office due to fear of stigma, concerns that supports will not be helpful, and the need for documentation. They overall expressed that they felt the SSD office is understaffed and under resourced.

The majority of students who were interviewed did report anxiety around using the SSD office due to having heard negative stories from friends who have disclosed, having a bad experience themselves, or hearing from friends that services are not helpful (Appendix B, C, and D). One student said that her housemate attempted to get services and it was a "horror" story so she did not want to try herself, but she did not specify what happened to her friend (Appendix C). Another student stated that when they disclosed their disability, the reaction from professors and staff in the offices was to question if the student can study at the university level (Appendix B). Another student said their friend had the same reaction when disclosing. Others were more concerned that the accommodations would not give them the help they needed—for example, one student explained they do not need extra time on tests, but they need extended time overall on assignments (Appendix C). According to them, this is not a service the office provides therefore they feel accommodations are pointless. Another student said they feel it would be a waste of time to even see what services are offered because they have heard other friends with similar stories about not using their accommodations. The students, in general, agreed that the SSD office is limited due to being underfunded, and, they felt, with the right funding it would be able to provide more support.

One student stated that he did have services that were really effective for his learning disabilities, and that the office has helped him adjust when needed. He feels his time at

Binghamton University has been enhanced due to the office's support. Part of the reason he is involved in student disability clubs is to help students navigate the SSD office because he feels it has a lot to offer if students are able to utilize it correctly. He noted, however, that the physical disability support was lacking.

Students with physical disabilities expressed that they felt the BU campus is not accessible (Appendix D). They reported difficulty getting around campus, and the few supports the campus provides for transportation are often very restrictive. The students explained their understanding of the policy was that students can only utilize accessible vans and buses in specific hours that need to be planned well ahead of time. They explained that sometimes students with a chronic disability do not have control over a flare up so are not able to plan so far ahead, and if the student needs to cancel, they can be punished by eventually losing the service. The student pointed out again, that with a flare up they might need to cancel at a rate differently than a non-disabled peer. They said it felt like a lose-lose situation. Students with physical disabilities typically can not "opt" out of using accommodations, the way some of their peers with learning disabilities have decided to do. For students with physical disabilities accommodations might be needed for safety reasons and for access classrooms, study spaces, and living areas.

Others stated they feel turned away because of obstacles of obtaining the needed documentation and expressed difficulty in getting an official diagnosis (Appendix C). In general, they understood they needed documentation, but students had varying understandings of what that entailed. Some felt it needed to be from high school, while others simply can not get a diagnosis due to cultural, financial, or other personal reasons but identify as neurodivergent and recognize they need services to achieve their educational goals. In general, students felt that the process to get

accommodations and find what accommodations would work for them is a frustrating and long process.

Despite all of that, students agreed that a primary reason students avoid the SSD office, and decline getting disability support, is due to stigma (Appendix C and D). There is a fear to even walk into the office due to worries of what peers, professors, and family might think. The SSD office concurred that stigma is a huge reason students don't reach out to the office (Appendix A). They added that when students do reach out they sometimes do not know what accommodations they need, due to being diagnosed later in life or never having accommodations that worked in high school.

Dr. Szymanski explained that students often think they need more documentation than they actually do (Appendix A). She said they just need documentation from a medical provider saying that they have a certain disability. Students are protected by the ADA to essentially "level the playing field" so students with disabilities have the same opportunity as students without disabilities. Dr. Szymanski explains that the challenges students have with the SSD office typically arise if the students never had services before attending college. Students who get diagnosed in this stage sometimes do not know what services would be helpful because they have never had them before. In these cases, there is sometimes a gap between the diagnosis and the student's perception of what they need. This can lead to a long challenge of trial and error to find the right support, which can be defeating. Sometimes students will not even bother trying other methods and just push through without using services.

Theme 2: Students recognize there is some privilege in having a diagnosis, and that a students' intersecting identities can impact their access to a diagnosis. As a result, students want self-diagnosis to have more validity.

The second theme that emerged throughout the interviews was the importance of noticing how different students' identities impact and overlap with their disability, and how that relates to the privilege in getting a diagnosis. In some cases, and for some students, a diagnosis might feel like getting a target, but for other students they see it as the only way they can access services. In general, students talked about how identity and privilege play a huge role in accessing disability services. One student noted that in his club, it is typically only the straight, white, cisgender members of the group that have accommodations, including himself (Appendix C). He said that he recognizes having accommodations in high school is a privilege, and that he had a parent who advocated for him which made this whole process easier. He states that these privileged identities have helped this process and said that it is important to consider how different identities intersect with each other and disabilities.

Another student, who identifies as a woman of color, mentioned that she was raised in poverty by a single mom who did not have the knowledge or time to advocate for her diagnosis. She feels she is struggling in school and in life, but because she learned how to "function enough" she now can't even get a proper diagnosis. She feels her GPA would be much better if she had just a few accommodations to support her neurodivergence.

One student expressed she is unable to receive a diagnosis because of cultural reasons. In her family and culture having a disability is considered a failure. She wants to get services but is unable to because of how it interacts with her culture and other identities. She explained that her provider told her an assessment could show up on her insurance, and that she needs to stay on her parents' insurance. These intersecting identities are a primary reason the students felt self-diagnosis should be more commonly accepted in some cases.

Dr. Zilvinskis mentioned the intersecting identities of age and disabilities, specifically for students who are diagnosed later in life, or diagnosed during graduate school (Appendix E). They are processing what new services and accommodations they might need, but also processing this new aspect of their identity and how it has related to other parts of their life. He mentioned how intersecting identities of disability and location where one is raised might also impact their ability to get diagnosed early on. For example, some rural schools simply don't have the resources themselves to support disabled students during K-12 education.

Dr. Szymanski also noted the importance of intersecting identities and privileges (Appendix A). She explained that the way low-income, transgender, and disabled people of color are impacted by their combining identities in ways that disabled individuals who also hold privileged identities such as being cisgendered, White, and financially stable are not. For example, middle class families might have an easier time navigating the SSD and college systems than a low-income or first-generation student because their experience with disability services prior to college. Dr. Szymanski explained that students receive their initial diagnoses in college have a harder time finding out what accommodations work, or simply don't seek the office out because they've already found ways to work with their disabilities even if supports could have made it easier. These barriers to diagnosis is a major reason students wanted some type of support for students who have to self-diagnose.

A couple students mentioned self-diagnosis would also help underserved students because college is already an extremely taxing time financially so adding the medical expenses of assessments and doctors' appointments is costly (Appendix B). This is especially true for students who feel they need support around ADHD or ADD, but need a diagnosis before they can access services. For an ADHA diagnosis they need an off-campus provider to give their assessment, and

this can be difficult for students due to transportation, lack of knowledge of local resources, and lack of providers in the area. The office does provide a list of providers, but students have expressed negative experiences with several of these providers as well as the concern that their parents might have access to some of their records due to health insurance billing procedures. They also noted that the diagnosis process can take a lot of time. The students explained that they are already in need of extra support and struggling, so they found it difficult to reserve the time and energy for a diagnosis that might result only in services that might or might not work. Instead, students would rather struggle and just try to complete their degrees without accommodations. This struggles and concerns also provided the motivation for the student disability clubs on campus (Appendix C). Student founders knew they needed support, and they determined support from the institution was too difficult to obtain. The students all agreed that disabled students are an oppressed or marginalized group within the university, but that students who are able to get a diagnosis do have privileges within the disability community, and that typically students with privileged identities have easier access to diagnoses and support.

Dr. Zilvinskis didn't mention self-diagnosis directly, but he did talk about institutions' different potential approaches and how that can impact students (Appendix E). If an institutional operational philosophy is a compliance-based model and they are doing the bare minimum to appease ADA and avoid a lawsuit, then their services for disabilities might be underfunded and under-resourced. This could lead disabled students to feeling like they aren't important. On the other end of the spectrum is a social justice model where the classroom is set up according to universal designed principles where all students are included despite accommodations. If more faculty and institutions approached disability through social justice models, then the inclusion of students with disabilities wouldn't depend on their accommodations or an official diagnosis.

Theme three: Students specifically seek social support from other disabled students due to loneliness, an increase in mental health issues, and lack of accessible mental health resources.

Dr. Szymanski and Dr. Zilvinskis both mentioned an increase in students' disclosing mental health concerns and seeking out social support. Due to social stigma that has been mentioned throughout the report, it is no surprise that students strive for social support with other students with disabilities. Both the Disabled Student Union and the Neurodivergent Club were created to provide that support (Appendix C, Appendix D). Students mentioned feeling isolated and lonely. Students also expressed they strongly felt the mental health services on campus were lacking and therefore knew they needed to create peer support spaces.

At the Disability Research Symposium (Appendix F), Dr. Szymanski noted that in all of the faculty talks on their research there was "an underlining theme of relationships that everyone talked about" and that often this work "goes back to relationships." She explained that people with disabilities experience an internal struggle with engagement. They have to balance the desire to engage and the fear of being misunderstood. Building relationships helps people move past the fear of being misunderstood and people find like-minded communities.

The Neurodivergent Club wanted an open space for self-diagnosed people and exploring individuals. The goal is to be a space where anyone is welcome to come and talk about experiences. They also engage in peer education to share resources on and off campus, along with general tips of managing their life with disabilities—for example, providing peer support of how to manage certain executive functioning concerns. The DSU started with the same goals. They want to create a safe, welcoming space for students with disabilities to comes together as well as advocate for each other. Students expressed that they felt there was not enough mental health support on campus.

Dr. Zilvinskis also experiences positive outcomes when he self-discloses his disability to his classes (Appendix E). He said that students typically disclose directly to him more often than they do through the SSD office once he has self-disclosed. He also gives opportunities for students to disclose though reflections on the first day of class, and he attempts to create is classroom environments that are universally designed so that everyone can be included regardless of accommodations. He feels his transparency around disabilities helps students feel comfortable, and then he can support them directly, but also refer them to the SSD office when needed. He has recently noticed an increase in students with mental health issues who receive accommodations for these concerns.

In the interview, Dr. Szymenski mentioned that disabled students regularly experience isolation in university setting, and there is in increase in mental health at this time in students' life due to age and transition into college life. The transition can be hard and overwhelming for students which leads to increased mental stress. The early-20s is also a common onset for some mental illnesses. Students are adjusting to these new stressors so mental health accommodations are becoming more common. The office can help with certain accommodations, but the mental health support comes from the University Counseling Center (UCC). Unfortunately, students overall feel the UCC is not accessible (Appendix C). Students mentioned negative experiences with the University Counseling Center. This included lack of appointments available, the ten appointments per person limit, and the staff not understanding students' needs. In general, the students felt that the UCC was even more underfunded and under resourced that's the SSD office, and they felt the university needs to support the mental health of students more. They found peer supports their biggest resource in college.

Theme four: The importance of the tenet of "nothing about us without us" within the disability community.

Both Dr. Zilvinskis and Dr. Szymanski discussed the importance of the "nothing about us without us" principle (Appendix A, Appendix E). This is the concept that disabled individuals need to be involved in everything related to disability life—including disability activism, research on disability individuals, and law and policies created around the disabled community. Dr. Zilvinskis mentioned the importance of community participatory action research.

This is also why the TAAG, Technical Accessibility Group, committee was formed on campus so faculty and staff can look at all the electronic materials and consider If they are accessibly, and do outreach to other faculty about accessibility (Appendix E). Along with Dr. Zilvinskis, the committee contains staff from Division of Diversity and Equity, Division of Student Affairs, the SSD office.

The Neurodivergent Club was created in part because the only autism group on campus catered to families and allies speaking for neurodivergent students and children, instead of providing support for self-advocacy and activism (Appendix C). Students were upset to find that this group supported the nonprofit "Autism Speaks" — a group that the Autistic community in general finds problematic due to the organizations goal of finding a "cure" for autism, promotion of Applied Behavior analysis (ABA), and its history of non-autistic people speaking about the needs of autistic people. The Neurodivergent Club members explained that they wanted a group "for them" rather then "about them." Disabled people need to be involved with choices made on behalf of this community. The Disabled Student Union also wanted to create a space for disabled students to be with other disabled students. They commented that the club is "for us" and "by us."

This theme also emerged throughout the Disability Research Symposium (Appendix F). Dr. Zilvinskis stated that a large reason he organized this symposium was to network with students with disabilities so they could know more about the research being done about their community. He said this is important because research needs to be "with" instead of "about." Dr. Jackie McGinley discussed her research with individuals with intellectual disabilities and how she gets involved with the community rather than just writing "about" the community. Her tenets were "empowering" people, "advocating," and "building and supporting programs" with them. Dr. Ron Gabel disclosed that he has a stutter so his research on speech therapy and stutters is being done directly by someone from the community. In all these cases, disability work included disabled people having a say about what is being done.

#### **Recommendations**

Based on these themes and experiences we put together recommendations for the institution to make students feel more supported. Based on the interviews, students have specific accommodations they felt would help them overall; students feel more mental health services are needed; and students would benefit from an increase in faculty understanding universal design to accommodate for students who aren't able to get official diagnosis. Other ideas based on conversations that arose at the Disability Research Symposium around the importance of relationships include having a space for disabled students similar to the LGBTQ center or multicultural center, continuing research with disabled students, and highlighting disabled faculty, staff, and students.

Students made it very clear that they recognized the office was understaffed and under resourced. They wish more students could access services, but understand that the office does have limits. They wish they could have more flexibility with assignments and due dates. One student

explained that if his classes had some more consistency it would help. For example, one of his classes releases all the material weekly. He feels with an extra week he would be much more successful, but one week to complete it without advanced noticed is just too hard. Students said that it would help if syllabi were more structured and consistent between classes, and if instructors would not change the syllabi so often.

Students also agreed that more mental health support was needed. This is difficult because the SSD office has no control over students' access to the UCC or CARES team. The office can refer out, but these are separate offices. Students seem to know this, but still expressed frustration about the system in general.

Students understood that it would be a challenge to have self-diagnosis disabilities accepted, but they do wish they were able to find more support for their disability and had access to services. A solution to this could be training more faculty on universal design classroom tips, although there is no way to ensure faculty use these methods. Overall students felt the University should put more funding into the SSD office and this would truly show that the University cares about this student population.

The Disability Research Symposium had a large theme of the importance of relationships. Having a space dedicated for students with disabilities would help them build community. We also recommend continuing to do research with disabled student input and highlighting disabled faculty, staff, and students so students can see that representation is important.

#### Limitations

Some limitations we experienced were only having a few months to work on the project.

With more time we would have been able to interview more individuals and departments. Another

related limitation is that we only have qualitative data. With more time and resources, we could have done a blind survey to have a better understanding of how many students on campus have disabilities, the percentage who use SSD, barriers to access, and kinds of support students have and need.

#### Future goals and research

In the future we suggest a survey is done on campus to gather more information on how students with disabilities feel supported on campus. Some of the important questions to consider include if they feel supported academically by the school and/or socially by peers. Focus groups might also be a helpful component to add if they would give further insight into what students are specifically feeling. Another goal would be to learn more about the physical TAAG committee that the university is working towards creating. It would be an important consideration to have students with disabilities continue working on this research: as noted throughout, a tenet of true activism and research within this community is "nothing about us without us."

#### Conclusion

The goal of this study was to get an overview of what services Binghamton University provides, what services students use, and how students feel about those services. Through interviews of student groups, the SSD office, and faculty we were able to find four overlapping themes discussed above, and recommendations to address ongoing concerns. This information can give the institution, student groups, and researchers some background about what to consider as they move forward in looking into ways to support students with disabilities better. We felt it was also important note that there is a privilege in being able to talk about disabilities, build these communities, and a privilege in being able to proudly claim a disability regardless of diagnosis-

status. Dr. Szymanski explained that recent university policies changes that designate "accessibility" an "Diversity, Equity, and inclusion" (DEI) topic (Appendix A). Legislatures and university governing boards in states like Florida, Tennessee, and North Carolina are now banning DEI work. Disability offices are having a harder time supporting students in these cases. Dr. Szymanski stated, "Accessibility isn't a debated right, and, yet, it all of a sudden is again." While Binghamton University's disabled students are fighting a challenging battle, other states are undoing these basic protections their students have. In some of these states, Disabled Students Unions might be more needed then ever before, and the way offices and institutions respond to these national policies will be telling for disabled students.

## Appendix A: Interview with Dr. Christen Szymanski, SSD office Director.

Meegs interviewed Dr. Christen Szymanski the director of the SSD office on Friday, March 10 2023 from 1:30 pm – 2 pm over zoom.

When asked "what services are most used by students?" Dr. Szymanski explained that there are not specific services most students are using, because the office works specifically with students to decide which services they need. Access to all services so depends on what they need. If they don't need help with study skills, they don't get success coaching. Services are individualized, depending on what students need. She explained that sometimes there are gaps between what the office and students consider a service (e.g., academic advising).

"What are the biggest challenges that students face with services?" The biggest challenge depends on what the students need. The office gives them supported help to find those needs, but students do need to have some idea of what would help and sometimes students aren't yet aware of what that is. The SSD's job is to provide accommodations that grant equal access to education, essentially to helps level the playing field. So for someone with dyslexia that might look like needing extended time on a test, while someone with mental health would need a Counseling referral. There are 1600 students, and the plans the office makes with each of those students will look different. The challenge is supporting them all in the way they need, as they are still learning what they need.

Dr. Szymanski mentioned that some of the specific challenges students face are that they are sometimes disconnected from what they need. College is a time of change and transition for young adults so they are learning new limits and new aspects of themselves that can include new disabilities whether they are learning, physical, or mental- and life changes which can also lead to

disabilities, illness, and injury. This is especially notable in the year 2023 as students are still adjusting to being back in-person after years of quarantine. In general, there is a disconnect between what students need and students' knowing how to get it or recognize what their needs are. Students who know what they need to succeed academically can engage in what they need; if they don't know, the challenge is to help them recognize how to use support to discover what helps and circle back to the SSD office. When concerns are stress related, it gets more complicated and a referral to the counseling center is a typical starting point to get that initial support. Another common challenge is getting a diagnosis and the follow up with the medical office and SSD. The office can help get initial referrals and once a diagnosis is received they can work with the professors. For students with mental health needs sometimes the support will look like the office reaching out and explaining that the student had a panic attack. She also mentioned that often students think they need more documentation than they need. All they need is a note from a PCP saying what they have and the office will support with the rest. The last challenge was the stigma. A lot of students don't want to reach out because they don't want an official diagnosis. Some students who do have documented disabilities don't want to come into the office because of stigma. Also, the fact that mental health concerns often appear at this age complicates these issues more.

Dr. Szymanski mentioned that her office is thankful they can even do outreach and support students because in other states like Florida, Tennessee, and North Carolina, faculty and staff are losing the right to talk about accessibility needs for students due to new policies. She explained they are considered part of Diversity, Equity, and Inclusion (DEI) initiatives which enables programs to be cut despite federal law. The offices are being stripped down to the bare minimum which essentially stops the students from getting the adequate support, and these offices also

cannot do outreach. Dr. Szymanski stated, "Accessibility isn't a debated right and yet, it all of a sudden is again." So she feels her office has privilege to still reach out and support students.

We asked if there was support from campus, state, or local agencies for the SSD office and students with disabilities. Dr. Szymanski explained that there are local agencies that support individuals with disabilities like BOCES Southern Tier Independence Center county office (state and fed), On-Track NY (servers mental health), and job training SSDI. But the challenge is knowing where to look for these resources and the fact that funding is always being cut. We asked if there is pushback from campus, state, and local agencies, and Dr. Szymanski referred back to those funding cuts. It's hard to support systems with few resources. She also mentioned the stigma again. Dr. Szymanski explained that a lot of people don't want to talk about disability or accessibility needs. She explained that, especially with physical disabilities, there is a lot of push back along the lines of: "Do you really want to be inclusive?" Or make spaces inclusive? Dr. Szymanski provided the example that if you request an interpreter, accessible entrance, or need specific lighting there will be pushback. She explained that people will not overtly say "you're not welcome" but often they just won't make it accessible which ultimately means you're not welcome. There is a balance of resources and priorities and that shows who is accepted and who is not. She mentioned hierarchy and intersectional issues around disability. For instance, how do lowincome, trans, and disabled people of color get impacted by their combining identities as opposed to disabled individuals who also hold privileged identities such as being cisgendered, White, and financially stable?

The last question centered on professional development for SSD office staff, and Dr. Szymanski mentioned several conferences in higher education have focused on students with disabilities as well as a New York specific one called AHEAD.

## **Appendix B: Interviews with Individual Students**

While speaking to a student who is not registered with the SSD, they shared, "I tried to register with the SSD and during the interview I was honest about my psychiatric history and the struggles that I currently deal with...it was like the SSD used that as ammunition, there was like this indirect threat that if I am having that many problems then maybe I shouldn't be attending Binghamton or living on campus." Another student who also is not registered with the SSD shared a similar sentiment, noting that they "cannot financially afford to see the specialists and have the tests/assessments done to get all of the SSD's required documentation...because of this, I am not eligible to receive accommodations or support of any kind." Other students who were interviewed noted feelings of intimidation, stress, and it being 'emotionally taxing' as reasons for not registering with the SSD.

The students interviewed who *are* registered with the SSD echoed a sense of disappointment and frustration regarding the accommodations that they do receive. One student recounted her experience with the SSD, saying, "While I do receive some academic accommodations through the SSD, it is not nearly enough nor does it really ease any of the struggle. For example, I have an accommodation that is due to my anxiety/ADHD/OCD where I can have extra time on assignments. The thing is, this only applies to assignments that you have less than 24 hours to complete normally. Meaning, if there is an assignment that is listed on the syllabus in the beginning of the semester that has a due date midway through the semester then there is *technically* over 24 hours to complete the assignment so I won't be allowed an extension of any kind through the SSD. Professors often try to find loopholes in the SSD's rhetoric, and sadly, they are successful in the endeavor." Another student said that "when I had initially met with the SSD about registering with them, after I basically laid out all of my struggles and illnesses, they

to see a list of possible accommodations and be like 'yeah this would actually really help me because abc'; rather the person who interviewed me thought about what they assume would take care of my needs and that was all I was offered. I found out about an accommodation offered through the SSD from a friend and having that in place would have *really helped me*, but I was never even given the option." While the students who were interviewed recounted very different circumstances and experiences, their tone remained consistent: the support that they are receiving through disability services is not sufficient.

## **Appendix C: Neurodivergent Club**

April 19, 7:30 pm-9 pm

1. Why did you decide to start this group?

This started as a Discord server for people with autism and was not super active. They wanted a bigger presence on campus, and the Autism Awareness Club was not what they were looking for. This club was more focused on advocating for autistic people and raising money for Autism Speaks. The members explained that Autism Speaks is a nonprofit that claims to support autistic people but actually speaks for them and "promotes eugenics." They felt the club did not have students who were autistic, so they decided to start their own club. The Student Association chartered them in March of 2023. They have about 20 members who are regularly involved and about 60 who are on Discord. One member expressed that they were struggling with mental health and neurodivergence, but they are self-diagnosed and couldn't get as socially connected as they wanted to: "I could hear people hanging out and I felt alone. I wanted to create a space that is open and welcoming and a place people could talk about their experience as a neurodivergent person at Binghamton."

2. Have you received any push back from campus departments, peers, or other orgs?

Overall there has been a lot of support. There is a lot of communal support. The SA was happy about it and surprised the club hadn't been created before. Some people do "troll" them on the Discord. That is where they get the most pushback and name calling. The school itself is mostly supportive and helpful. They've had some issues with getting chartered simply because of the process, and they are worried about the potential of funds, but overall they feel supported. Some students bully them and say things like they don't think neurodivergent should be in higher-ed, and they have been called the "r"-slur. In response to that they said, "so we are also combating stigma."

#### 3. What are the main goals?

They stated the main goals are social support, help students get connected with services that pool together resources, and peer education on school policies. They want this space to be open for self-diagnosed and exploring individuals. The goal is to be a non exclusionary space where anyone is welcome to come and talk about experiences, a place for students to have communal support. They promote education for other students on campus about neurodivergent people and work to break the stigma on disabled students.

## 4. Do students in your org typically receive services for BU?

The majority of the students don't have accommodations. The ones who qualify don't receive them. One member mentioned being "too scared" to go and work with the office on a different accommodation because of the fear that they won't do anything differently. They stated that they have extended time on tests, but that doesn't help. They need extended time on assignments in general. Another member does get accommodations, and they do work for him. He uses a word processor and gets time and a half, which were the accommodations he had in high school and they worked for him then as well. Another student mentioned that it is hard because students have to be proactive in the process and that can be extra difficult for students with disabilities. Another member expressed he receives accommodations that are okay, but not as good as they can be. He mentioned that he finds it interesting that typically only the straight, White, cis members of the group have accommodations, including himself. He said that he recognizes having accommodations in high school is a privilege that can make this process easier. One member said that it is very scary to reach out because she had a friend who did and they had a terrible experience. She said hearing this story made her never want to go. The group mentioned that the SSD office in general does better with learning disabilities, but there is even less support for physical disabilities. Overall, they feel SSD needs more funding.

5. Do you or anyone you know NOT use services but need them and why aren't they being used?

One member said she needs services but doesn't have them because she can't get them. She didn't have a diagnosis in high school because she had a single mom who was working a lot and they come from a lower-income background where the school support services were also not great. Her mom's first language was not English, and her culture and community had a lot of stigma against disabilities including mental health. She has since tried to get support for being neurodivergent but has been masking her whole life and has been declined an official diagnosis because she is "functioning" enough. "I feel like I'm struggling," she stated "If I had more time on tests maybe i wouldn't have had to change my major. I felt I had to shift my major to something more writing focused." I followed up with "what were the struggles you were experiencing" and she explained, "Turning assignments in on time. Just some buffer with that would have made my GPA so much better. I would be doing a lot better if I had some of these services."

Another member said she does have a diagnosis and had since high school, "but I never really was able to use accommodations I was given in high school because they didn't follow through with their policies, so now I don't really know what works for me or what I need. The regular services don't help me. I need support with time and focus, I need some extra support with understanding and staying on track. I have a hard time with math and understanding but I don't think they can help that." She also mentioned she feels migraines deserve more support along with other physical health concerns. "I've been told they can't do anything for me about that. That's something I'd hope they'd work on in the future, and it'd be nice if they offered more for mental health."

The other members chimed in that they should offer more counseling and ten sessions is not enough. They said the therapy model being only for the short term doesn't help students.

The services overall aren't being used because of access issues, requirements, financial reasons, and worries about health insurance. One member stated that she can't get an official diagnosis because if it shows up on her health insurance and her parents find out they would be very disappointed in her and could cut her off. She explained in her culture this is seen as a failure. She wants to access services but is unable to get a diagnosis and unable to gain services without one. She also mentioned it's just expensive and time consuming to go through the process of getting diagnosed. Another member seconded this. He said the time and money to deal with a doctor while attending school is just not worth it.

# 6. What was the process of getting services like?

Some members said the process was very simple and easy, but that they also had documentation, support from parents, and previous accommodations from high school. Another member said the process was scary and they rushed it due to anxiety. The self-diagnosed students expressed feeling turned away.

# 7. What services are missing?

They said the big services missing are physical health services like wheelchair ramps, handicap bathrooms, elevators that work regularly, doors being light enough to push open, along with support around migraines and other physical disabilities. They said mental health support is very much lacking and the university needs to find a way to expand the mental health services. Lastly students flagged the lack of services around executive dysfunction; they explained a lot of the services still expect the students to act in neurotypical ways. One student explained his time

blindness is part of his disability, and they don't work with that and essentially tell him he needs to work on that. He feels it's counterproductive because that is a component of his disability.

8. What is stopping students from accessing services?

They said "fear," "feeling like it's not like its not going to work," lack of resources that other students have like insurance, documentation, parents' support, and stigma from professors and other students. They also mentioned that there is this new concept of neurodivergence as a trend, which is feeding into the stigma. They explained they think it's a positive attempt to normalize neurodivergence, but it's "washing it down." They said this has caused other students/people to call them fake and saying they are doing this for attention. "In the past people would just say I'm weird but now they are saying I'm faking or they say I can't have it because they have it."

9. In a perfect world (resources and finances aside) what would disability services on campus look like to you?

The biggest help the group collectively agreed on was having more time to get assignments in or at least some curve time on assignments. Next, they felt accommodations should be easier to access. One member said "the consequences of forcing us to prove these documents outweighs the pros of making it easier for students to get help. Students who don't have access to getting a diagnosis and students who want to avoid medical stigma should still have access to educational services." When it comes to specific support for students with ADD, one student mentioned again the importance of working with students who have executive functioning issues like time blindness. He explained, if assignments were standardized and published early on, if there were more uniformity with courses, and teachers front loaded the assignments in advance he felt he could keep up. He expressed, "I want to work ahead. There are some weeks where I have no time

and some where I have a lot of time. I'd want to plan better if I could, so having some uniformity would help." He explained that a lot of his classes randomly assign new assignments. He stated, "I once asked explicitly if I could submit a week late, but they declined it. My GPA would have been much higher. They declined it because I have to 'learn' time management but my ADD makes it so I can't develop that skill in the way they want. This shows a general lack of understanding about how ADD and neurodivergence works." Another student said, "I would just need someone to help map out the schedule and I don't have that type of support."

## **Appendix D: Disabled Student Union**

1. Why did you decide to start this group?

We mostly wanted to create a social support system for disabled students and help students pool together resources. Another group started around the same time that is similar and I wish we could be more connected. It feels like they want to separate themselves from the idea of being disabled because I don't know why they don't just join us.

# 2. Do you receive services?

Most of the students do receive services, but often they aren't used or they don't feel very effective. The support for physical disabilities is even lower. The interviewee expressed difficulty getting around campus, and noted that the few supports the campus provides for transportation support are often very restrictive. You can only utilize them in specific hours and you need to plan far ahead. They explained that sometimes if you have a chronic disability you won't have control of a flare up so having to plan so far ahead is not always an option. You also can get "punished" or lose some of those services if you cancel too much, but again, with a flare up you might not have control over needing to cancel. They expressed issues with advice and the disability office reaching back out, difficulty with some professors working with the chosen accommodations, and a lot of physical concerns with the school. We found that a lot of places aren't accessible in the buildings. There are often doors with no electric options. One of the policies I found most upsetting with the bus schedule. You have to put in your schedule before the semester starts, and night classes are too late for the service. The student said the bus often just passed them also, especially when they were sitting down.

3. Do you or anyone you know NOT use services but need them, and why aren't they being used?

A lot of friends need services but don't get them, mostly because of the documentation and because dealing with the office is just bad. They take a while to get back to you, and then the professors don't even listen to the accommodations. It feels pointless sometimes. It's already fighting an uphill battle just to be in school, a lot of people just don't have the time and energy to fight for this extra stuff.

# 4. What was the process of getting services like for you?

The process wasn't awful, but it wasn't very effective. I had a lot of previous documentation from high school which helped, but they still questioned somethings about my physical disabilities which felt weird. I feel kind of like a burden when I have to advocate for myself when it comes to my disabilities.

# 5. What services are you using?

I get extra time on tests and sometimes assignments, but it's not enough. If I could have like another week to get assignments in I would be in such a better situation.

## 6. What services are missing?

The mental health services are really bad. It's only for a short term which isn't helpful, and even in a crisis they aren't very helpful. The campus is very inaccessible in general for physical disabilities. Some buildings aren't accessible. There are often doors with no electric options. In order to use the accessible buses, you have to put in your schedule before the semester starts, and night classes are too late for the service. When trying to use other public transit, the bus often just passed them because they have to sit down for their disability. Having more flexibility with assignments due would be helpful as well.

#### 7. What is stopping students from accessing services?

They seem understaffed. They seem like they want to help, but there is only so much they can even do when the office is so small. Also documentation—students who don't have proper documentation just get turned away, but that's not always easy to get. Also the mental health services aren't great. Also stigma, no one wants to have a disability or admit it because professors and other students aren't always supportive. Some people who have invisible disabilities want to keep them invisible.

## **Appendix E: Interview with Dr. John Zilvinskis**

Meegs interviewed Dr. John Zilvinskis about best practices on 3/27/23 from 4:30-5 pm.

1. Biggest take aways from working with students with disabilities.

Some of the small stuff is most effective. "I have a note about my own disability in the syllabus, and a note about mental health supports as disability supports." A student specifically said the mental health piece was helpful because she never saw her mental health as a disability, so she was able to process that as part of her identity. "Students disclose with me quit often and talk about disability even above their accommodations letter. In a lot of ways this is helpful because accommodations are based on the undergraduate experience, so like extended time on tests doesn't mean anything for any of my classes." Also, in a lot of classes after going over the syllabus I will ask as reflection question. "Now that you're familiar with the goals of this course, what aspects of yourself might influence your success over the semester. Sometimes students disclose here if they want to. All of those small things will build a foundation and then I will use my disability scholar stuff to help students understand the concepts of "disclosure" or "stigma" and often students will state they didn't know these terms before. This helps students categorize their experience.

2. What do you know about disabled students and activism, specifically at Binghamton?

I'm teaching a disability in higher education course. In the book we're reading one of the chapters is about history of disability and another is models of disability and both interact with historically examples of activists, and the models of disability and that action and activism is part of the experience. Improving the experience of peoples with disability is always a goal.

At Binghamton, before Covid, we had this event under the previous SSD director. The event was "Disability as Diversity." It was different organization, not all disability centered, but included orgs interested in making their clubs or orgs more accessible. For example, students with depression could do "this" or we could think about "this aspect" of the org to make it more

inclusive. It was an inventive genuine way to talk about disability, and they seemed to be the authority over their needs. This was really impressive.

Now that quarantine is over, people are back on campus, and we have a new director. There is a new group the SSD office is working with – the Disabled Student Union. I am unsure the level of activism but I think that is a component.

The final point on this, is the importance of Community Participatory research and the slogan for disabled activism is 'nothing for us without us" the chapter on CPR mentioned this slogan and explained that disabled individuals should be on research teams to authenticate and connect the lived experience of the research to the group.

3. What is going well and what could improve when supporting students with disabilities?

Dr. Zilvinskis explained that Binghamton University in general is focused on undergrads so for him at the graduate level, understanding disabled students is slightly different. This is not unique to Binghamton, but in general University's focus on accommodation for undergraduates. For some graduate students in STEM fields these accommodations might still

Also how do students feel about their accommodation letters? How does that impact their identity or understanding of their disability. He was curious what happened with students who don't reach out.

be helpful, but in a lot of programs we aren't doing that type of education as much.

4. How does this impact Phd Students?

The main thing I notice for phd students is the concept of "crip time." It's a reclaim of the slur "cripple" used by some in the disabled community to acknowledge the idea that society is built on ablism norms and functionality so sometimes people with disabilities it might take longer to do something. An example of this is someone with a physical disability getting ready in the morning.

It might take longer than someone who is temporarily able bodied. This is true for students completing a Phd or dissertation program, but we have fairly strict time lines around this as well.

# 5. Does this work for/apply to Phd Students?

There are also a lot of people who realize they are disabled later in life and how it impacts them and their identity. In my own experience realizing I had dyslexia, I knew I always struggled with reading and spelling growing up, but not until doing a research project during Phd when realized the extent. I started using a screen reader to get research data done quicker, but then he started using the e-reader to just read and for almost all engagement with literature. One day I was having lunch with my mom, and I said I think I'm dyslexic and she said "oh yeah, you are." It turns out the small rural school he was attending wouldn't pay for the testing, so she attempted to work with specialists on her own and the advice she got was to just keep working with him and reading to him. It did eventually click, but it might have been easier. This happens a lot to phd students. It's partly coping with the disability but also coping with the new identity. PhDs are notorious for "Incompletes" so these new personal developments on identity might be a component of that.

#### 6. Anything to add?

As faculty, one of the things you have to tease out is what is the philosophical bearing of your institution when it comes to disability. The lowest end of that would be a "compliance based organization" that is only engaging to appease the ADA and avoid being sued. This can be hostile for students with disabilities. Disability resource staff can be understaffed, so too much heavy lifting without resources, which ultimately sends a message to students that they are a nuisance, rather than that this is an aspect of identity that needs to be considered. The farthest end of this spectrum is a social justice model, which asks the questions "so how do you create educational spaces so they are accessible to everyone without a request?" This idea of universal design that works for everyone. I'm on the TAAG, technical accessibility systems group, a committee of

faculty and staff that looks at all electronic materials to review their accessibility, and then also do education and outreach to other faculty about disability. It consists of 1 faculty member, staff from the Division of Student Affairs Office, staff from the Center of Teaching and Learning, staff from SDD office. They are also making a new, physical version, that will work with faculties and space.

This is an interesting committee because you see how the philosophy of individual actors, along with how that actually matriculates to the school. How much do faculty treat disability as an accommodation thing verse inclusion as an ultimate goal? What is the culture of the institution, what is the climate like for students with disabilities and how do they communicate those things? This can be touchy because the SSD office has their philosophy and their actions, but the university has their actions. The university might think they are striving for social justice, but the implementation actually is not what they intended. And this is at any university. So a big take is reconciling philosophy and recognizing what is in your locus of control. So in my class I try to practice a lot of universal design and inclusion pieces because I can control that space, and then also work with TAAG to make some more large scale change.

Dr. Zilvinskis and a few other faculty are also holding a "Disability Research Symposium" highlighting research that faculty and students are doing on disability-related services on May 5<sup>th</sup> 2023. He again reminded that a big component of this is the idea of "not for us, without us" so having the DSU involved and other disabled students and scholars was a key component.

# Appendix F: Summary of Binghamton University's Disability Research Symposium

On May 5<sup>th</sup> 2023, Binghamton University's College of Community and Public Affairs' Student Affairs Administration department and the Services for Students with Disabilities office held a "Disability Research Symposium." The goals were "to Connect disabled folx across campus, and to Foster disabled attendees seeing themselves in research." Faculty members presented on the research that they're doing on individuals with disabilities, Dr. Christen Szymanski talked about how this research relates to the office and her general thoughts on the research. After these presentations there was networking where faculty, staff, and students could discuss research interests and listen to poster presentations about researching for students with disabilities.

Dr. Ron Gabel from the Department of Division of Speech and Language Pathology spoke on his lived experience with a stutter and his research on speech therapy and stuttering. Dr. Loretta "Lucky" Mason-Williams, of the Community Research and Action program and Teaching, Learning and Educational Leadership, discussed her work as a special education teacher and supports to make special education teachers stay in the field longer. Dr. Jackie McGinley talked about best practices with working with people with intellectual disabilities, and end of life care. She specially talked about how to support people having the care they want and the dignity they deserve. Dr. John Zilvinskis discussed his experience of receiving diagnosis with dyslexia late and his work on supporting students with disabilities. He discussed the importance of starting to do research on specific disabilities instead of seeing disabled students as a monolith, as well as looking into how other identities impact disability. For example, if an institution is making policy for disabled students, but aren't considering how Black disabled students experience differ from white student, then the policies will never be all encompassing.

Dr. Christen Szymanski spoke next on the themes she noticed across the faculty's research. She stated that she noticed "an underlining theme of relationships that everyone talked about. It all goes back to relationships." Students having allies and support makes a huge difference in their experience. She explained that people with disabilities experience an internal struggle with engagement. They have to balance the desire to engage, and the fear of being misunderstood. Relationships help people move past this fear of being misunderstood. "We know where people are in moments like this and where we can go." Relationship building also leads to change. She explained that she has been building a relationship with physical facilities, and they recently created QR codes to report if accessible door openers were not working. This will hopefully lead to doors getting fixed quicker. She is also working on having more captioning across campus and working with the Disabled Student Union to get student feedback. She said events like this also help because faculty, staff, and students can see who else cares, so can build relationships and help advocate for each other.

After the speakers, everyone had the chance to view the poster presentations that the Student Affairs Administration Graduate students created for their student affairs elective course on working with students with disabilities. These presentations included research on disabled students involved in Greek life and their sense of belonging, Black disabled students sense of belonging, queer disabled students sense of belonging, and others.

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