WORKING REALITY

DISABILITY JUSTICE & EMPLOYMENT

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Disability & Neurodivergent pride flag

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Soul Touchin Experiences LLC

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Working Reality: Disability Justice & Employment
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Catalyst Consulting Associates
Sponsored by: SoulTouchin Experiences, LLC
September 2022

See the humanity behind each data point

Acknowledgements

This report would not be possible without the following people:

- Anita Cameron and Jeiri Flores
- Keith Jones, President & CEO Soul Touchin'Experiences & Co-Founder of Krip Hop Nation
- CripCreate
- Claudia Alick, Calling Up Justice
- The Curiosity Paradox
- The Neurospicy Network
- Tiffany Joseph, Nigh Functioning Autism

and so many more!

"

This report is a sobering gift to the national movements for equity and justice. The systemic analysis through an intersectional Disability Justice lens reflects local disparities that verifiably match similar disparities across the United States. We welcome communities, institutions, and funders to see this report as a guide to accept collective responsibility for the seemingly perpetual failures made on behalf of multiply-marginalized Disabled people.

It is also important to note the centuries long legacy of gatekeepers and institutions refusing to believe the personal stories of Disabled people. This report's methods of personal story combined with demographic evidence helps to deliver some of the pressure necessary for service organizations to move away from the optics of equity towards real solutions to the problems facing multiply-marginalized Disabled people today.

"

-The Curiosity Paradox, Access Artists and Disability Equity Consultants

Author's Notes

This report is set up a bit differently than our previous report Employment Barriers for People with Disabilities in Monroe County and Rochester NY. For ease of reading, we used a more narrative style, and wherever possible there will be quotes or narrative coming from disabled people themselves. Additionally, the focus will be on non-white disabled voices as they are historically underrepresented in research.

In addition to ease of readability as a form of access, we have provided this report as a Word document, accessible PDF, an MP4, and visual summary. If any of these formats do not work for you, please do not hesitate to contact the author at hello@catalystconsultingassociates.com.

Methodology, Praxis & Terminology

Intersectional data is often difficult to come by for disabled people. Additionally, data often does not have the same numbers across sources due to when the counts were taken, estimates versus actual counts, etc. This report uses the Census Bureau's American Community Survey Estimate data, referred to throughout this report as the ACS. We also used a combination of the following:
- Focus group discussion (25 persons)
- A proprietary database we've curated over the years by cross-referencing various types of social media and hashtag reviews (over 2 million posts and over 300 hours of videos), as well as reading past public documents from county and city projects.

We also spent time in various neighborhoods and locations talking with disabled individuals. These methodologies were preferred as Rochesterians, stereotypically, have low response rates to surveys especially those in the disabled community. We understand that disabled people are wary of surveys, so spending time with the community and building rapport, was critical. We have also anonymized their comments and will not share the data because community members were afraid of not being believed of their lived experiences. We hope this methodology leads to a critical shift in how data is viewed: it is not the counts that matter but centering the voices of those who are disabled.

For clarification for our readers, we will be using identity-first language. We understand that many organizations use person-first language (i.e., people with disabilities). Additionally, the history of person-first language is rooted in parent groups and many disability rights advocates fighting for disabled people to be seen as people but, like with any community, language changes! Also, this author wants to acknowledge that many marginalized communities do not use person-first or identity-first language for how they describe disability.

Additionally, because race and gender/gender identity are used in an identity-first context, disability is treated the same in this report for consistency. Identity-first usage also aligns with our disability justice viewpoint where disability is another aspect of our identities that is not separate from race or gender. Furthermore, good policy-making needs to come from those who are most impacted and cannot hide their disabilities in any way. It is not that non-apparent disabilities do not exist but to highlight what leadership of the most impacted looks like and sounds like. We also are clear that systems of oppression exist and persist regardless of how a marginalized group personally identifies.

The goal of this paper is to update the landmark 2018 employment barriers report, as well as create a comprehensive strategic plan and recommendations for policy. Employment is more than just getting a job, it also includes the multitude of barriers that are informed by racism, ableism, capitalism, patriarchy, etc. in key areas from education to healthcare throughout the lifetime of an individual.

Author's Notes

We also understand that this work cannot be done by one organization alone, but that existing initiatives should embed the recommendations and strategy into their scope of work. Again, disability is not separate so the advocacy and community-wide strategy need to be intersectional and follow the principle of cross-movement solidarity.

The praxis of this author is disability justice. These are 10 guiding principles developed by Sins Invalid. This paper will focus on intersectionality and recognizing wholeness :

- Intersectionality - Coined in 1989 by Dr. Kimberlé Crenshaw, intersectionality was about the "isms" that impact black women in society, specifically racism and sexism. When taking a disability justice approach as regards employment, the intersections of racism, capitalism neoliberalism, patriarchy, and ableism all are interacting as barriers to disabled persons who want to work.

- Recognizing wholeness: disabled people are whole human beings with a past, present, and future. Throughout this paper, we will use quotes from those who are most impacted to drive the narrative.

For more information on all ten principles of disability justice visit the Sins Invalid website here: https://www.sinsinvalid.org/blog/10-principles-of-disability-justice

While there are multiple definitions for disability, we will use the same definition as presented in the 2018 report: a person with a physical or mental impairment that substantially limits one or more major life activities. The Census Bureau provides six categories of disability:
1. Self-care difficulty
2. Hearing difficulty
3. Vision difficulty
4. Independent living difficulty
5. Ambulatory difficulty
6. Cognitive difficulty

Where necessary, we've shown the difference between the Rochester city data and the Rochester Metro Statistical Area data. See www.catalystconsultingassociates.com in winter 2022 for interactive maps of the data!

Lastly, this work was reviewed by the foremost experts in disability justice, history, and policy. They bring nearly 500 years of lived experience to truly center the rallying phrase of the disability community:
Nothing about us, without us. This also is the first time a paper written for the disabled community of Rochester had oversight and approval from national experts on disability justice. And I hope this will be a model moving forward.

-- Luticha Andre Doucette
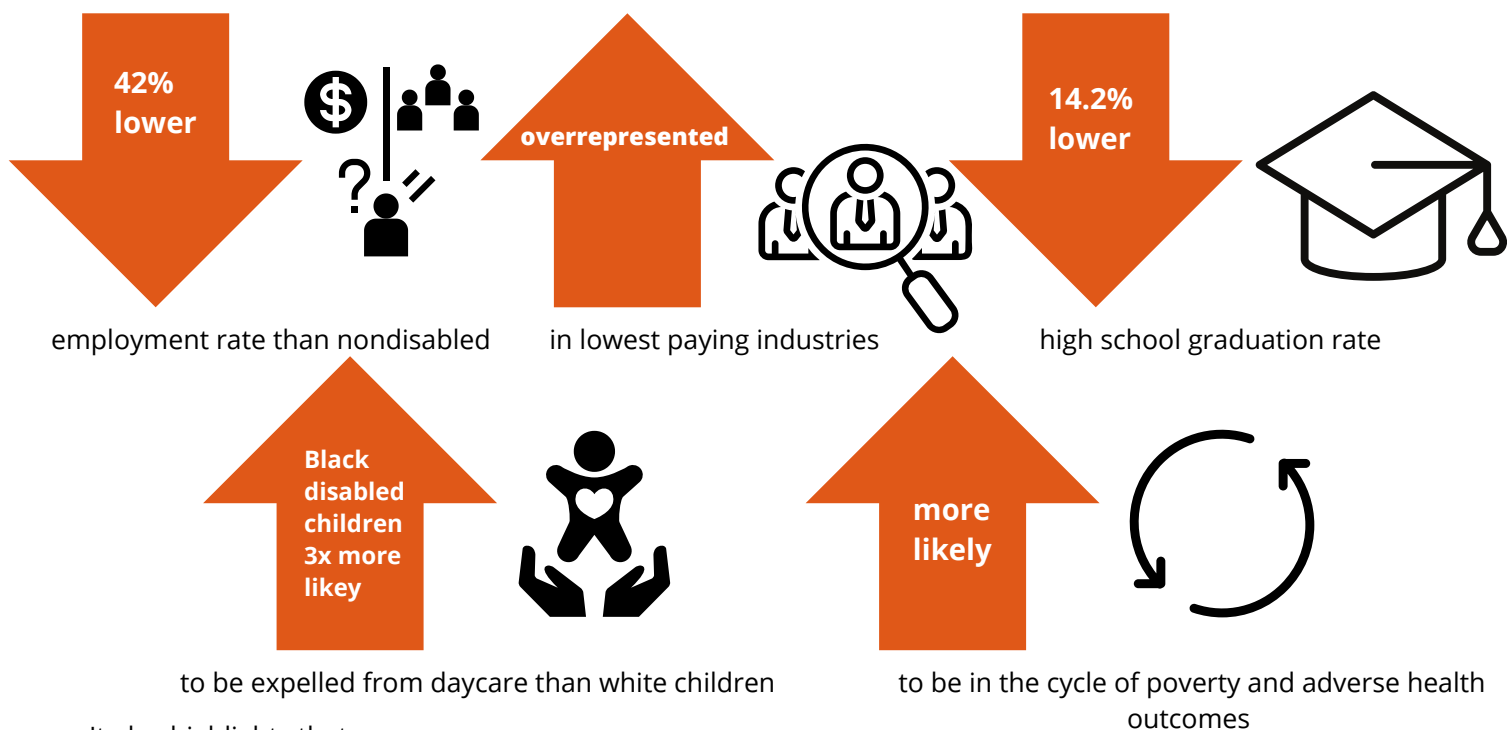Owner & CEO
Catalyst Consulting Associates

Executive Summary

This report seeks to update the 2018 report on employment barriers. It is a deeper exploration into the barriers disabled people experience from disabled people themselves as they are still an overlooked but key portion of poverty in Rochester and Monroe County.

The barriers disabled people have articulated are the following:
- Healthcare
- Housing
- Transportation
- Education
- Social Services/benefits
- Policies

With racism, ableism, sexism, and other factors informing the attitudes and decisions within those barriers. The barriers identified have been historically pointed out by well-known leaders and are embedded in key critical policies e.g. Olmstead and the Americans with Disabilities Act. They are also reflected in historical papers done in the Rochester community on key antipoverty initiatives, further reinforcing the need for explicit disability-related interventions. These barriers are exacerbated the further you get from major metropolitan areas.

42% lower
employment rate than nondisabled

overrepresented
in lowest paying industries

14.2% lower
high school graduation rate

Black disabled children 3x more likey
to be expelled from daycare than white children

more likely
to be in the cycle of poverty and adverse health outcomes

It also highlights that
- The vast majority of employed disabled people are under benefits cliffs such as the Medicaid Buy-in Program
- Disabled people who cannot enter the workforce are legislated into abject poverty
- Gearing policy and attitudinal change towards those who are most impacted (abject poverty class) benefits everyone

As the 2018 report stated, the Rochester community must take a proactive and intentional approach to include disabled people in the workforce and its anti-poverty work. Thus far, initiatives around antipoverty/diversity, equity, and inclusion have not proactively included disabled people. A renewed commitment with the disability community is needed so that we do not continue to leave disabled people behind.

In 2021 Forbes magazine indicated that the City of Rochester was third highest in the nation for overall poverty rates.[1] According to the 2022 ACS, the poverty rate of nondisabled persons in Rochester was 30.4%, and for disabled people below 100 percent of the poverty level was 39.6%, a decrease from the 42.1% from the 2018 report but higher than their nondisabled counterparts by nearly 18 percentage points.[2] It is unclear if this data was inclusive of the impacts of COVID-19.

Over the years many initiatives have been created to attempt to decrease poverty and the racial divide, however, as stated in the 2018 report, none had a very specific and clear disability focus as part of the work. Because of this lack of focus on disability, the 2018 report on employment barriers was commissioned by the University centers for Education in Developmental Disabilities (hereby referred to as UCEDD) and done in partnership with the City of Rochester and the Rochester-Monroe Anti-poverty Initiative (RMAPI).[3,4]

However, upon its completion, none of the recommendations in the report were included in community-wide initiatives, despite the Commission on Racial and Structural Equity (RASE) 2021 report stating that more detail and information was needed for the disabled community of Rochester. Even statewide, it is unclear how initiatives on employment for disabled people are faring.[5] In 2015, the state of New York launched its Employment First Initiative but as of this writing, there are no clear metrics on how the workbook and other links have helped disabled people or employers.[6]

It is important to note, that the categories identified as barriers overlap with key legislation such as the ADA and Olmstead and were also identified by the Bureau of Labor Statistics in a nationwide survey of 60,000 people in conjunction with the Census Bureau.[7,8] Justin Dart infamously spoke of these barriers in his house oversight committee address in 1987.[9] So these barriers are not new, as they have been the impetus for the disability rights movement and independent living movement for nearly 40 years, nor unique to Rochester and the Monroe County Region.[10]

So, what does this mean? It means that even within our intentional inclusive spaces, disabled people have often been invisibilized within social justice work and social change work in Rochester, NY. Additionally, when disability intersects with every other aspect of identity and the systems of oppression mentioned above have disabling impacts on people, it is imperative that the Rochester community at large be proactive about the inclusion of disabled people, especially in the midst of a disabling global pandemic.

This update seeks to build upon the 2018 report and fill in the gap of information indicated by the RASE Commission as well as key recommendations to begin to address the barriers impacting disabled people in Rochester and Monroe County.

Demographics

Like any report, let's start with the basics: who makes up Rochester's population? What does the data say about disability in Rochester, Monroe County, New York state, and the nation?

According to the Census Bureau's 2020 American Community Survey data, Rochester has a total population of 206,357 people with a median age of 32.
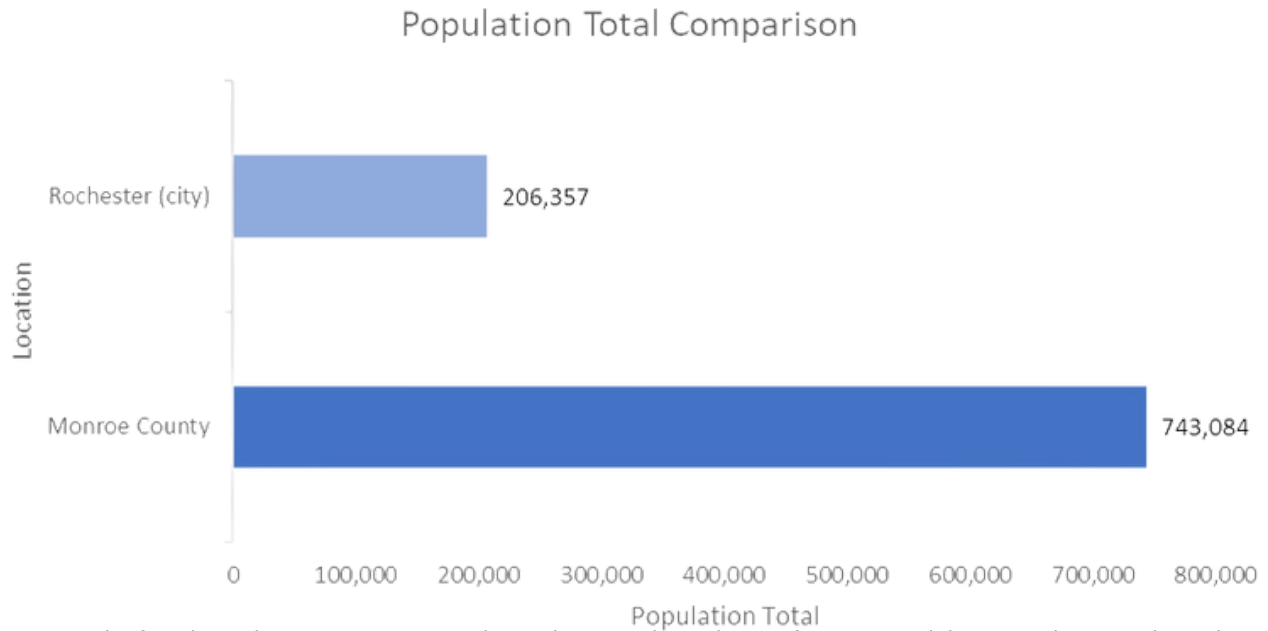

Figure 1. graph of total population comparison. Rochester has a total population of 206, 357 and the county has a total population of 743,084. Source: U.S. Census Bureau, 2016-2020 American Community Survey 5-Year Estimates

Image Description: Wall Therapy. Artist: Sarah Rutherford. Description: colorful rendering of singer Danielle Ponder, a chocolate skinned Black woman with a caramel skinned Black woman in a pink wheelchair sitting in front.

Percentage of People in Monroe County & Rochester with a Disability

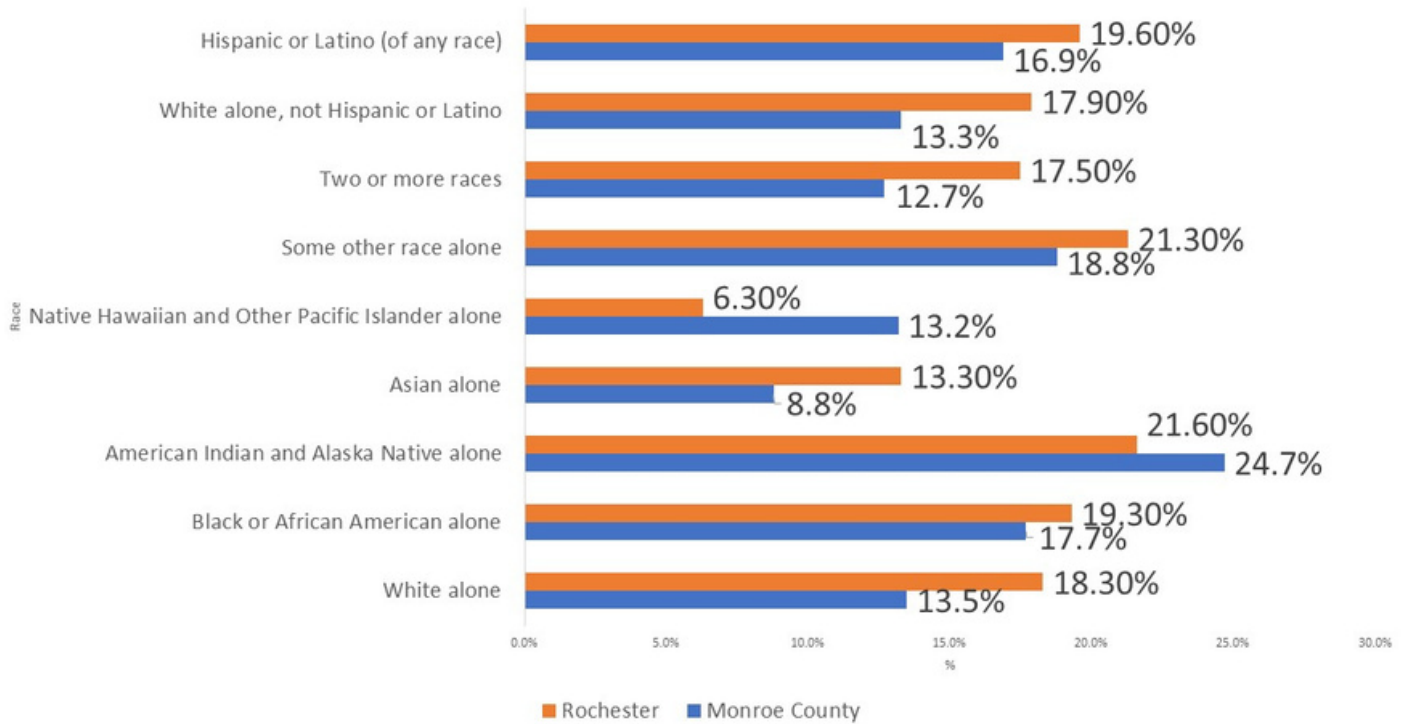| Race	Rochester	Monroe County
Hispanic or Latino (of any race)	19.60%	16.9%
White alone, not Hispanic or Latino	17.90%	13.3%
Two or more races	17.50%	12.7%
Some other race alone	21.30%	18.8%
Native Hawaiian and Other Pacific Islander alone	6.30%	13.2%
Asian alone	13.30%	8.8%
American Indian and Alaska Native alone	21.60%	24.7%
Black or African American alone	19.30%	17.7%
White alone	18.30%	13.5%

Figure 2. Racial breakdowns by percent for Monroe County and Rochester for disabled people. White disabled people (white alone and not Hispanic/Latino) in Rochester make up 36.2% of the population of disabled people, making them the minority of the population. Note: percentages do not add up to 100% Source: U.S. Census Bureau, 2016-2020 American Community Survey 5-Year Estimates

The City of Rochester is more racially diverse than the county. The majority of disabled city residents are nonwhite.

Those identifying as Hispanic alone is 19.6%, American Indian is 24.7%, Black is 19.3%, and Asian is 13.3%. These numbers differ from those who are disabled in all of New York State: Hispanic alone is 11.4%, American Indian is 17.6%, Black is 12.8% and Asian is 6.9%. Compared to the nation, Rochester has a higher percentage of marginalized groups who are disabled.
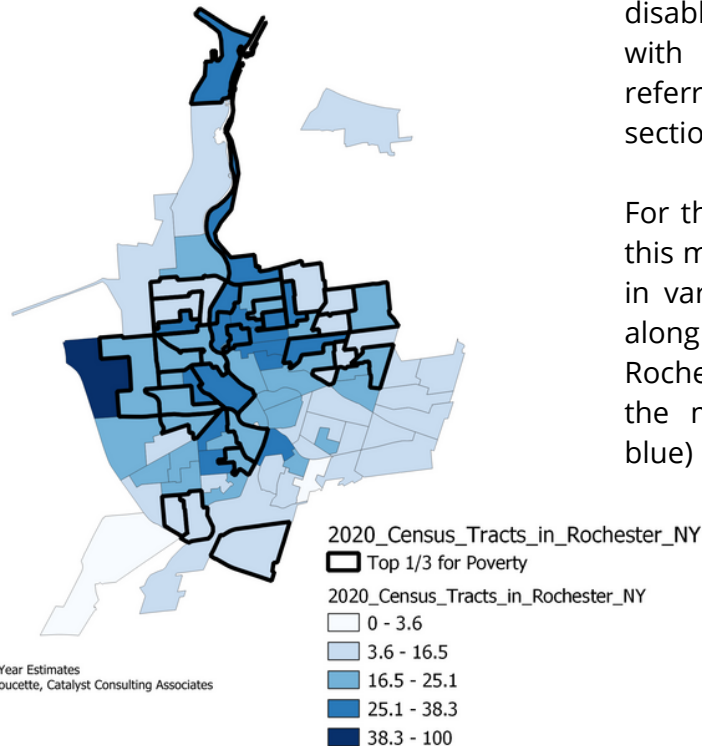
This diversity of disabled residents is why an intersectional approach to solutions is needed.

Image Description: Disabled and Here. Artist Chona Kasinger. Description: Three Black and disabled folx smile and stroll down a sidewalk side by side. On the left, a non-binary person walks with a cane in one hand and a tangle stim toy in the other. In the middle, a non-binary person rolls along in their power wheelchair. On the right, a femme gestures mid-walk.

Demographics continued

Disabled People in Rochester by Census Tract (All Ages)

2020_Census_Tracts_in_Rochester_NY
☐ Top 1/3 for Poverty
2020_Census_Tracts_in_Rochester_NY
☐ 0 - 3.6
☐ 3.6 - 16.5
☐ 16.5 - 25.1
☐ 25.1 - 38.3
☐ 38.3 - 100

Source: Census ACS 2020 5 Year Estimates
Mapped by: Luticha Andre Doucette, Catalyst Consulting Associates
May 2022

Like in the 2018 report, we overlayed the top third highest Census tracts for poverty with where disabled people live in Rochester.

It is important to note that this concentration and location of where disabled people live will intersect with other barriers so we will be referring back to this map in future sections.

For those unfamiliar with Rochester, this map correlates to others created in various reports and tends to fall along the "Tale of Two Cities". Rochester's east side (right side of the map, indicated by the lighter blue) is predominantly white. [11]

Figure 3. Map of Rochester by Census tracts. Disabled people increased on the west side (darkest blue) from the 2018 report but are still mainly concentrated in the highest third of poverty tracts.

The darker areas of the map are areas impacted by redlining and the building of the inner loop and other divestments in predominantly nonwhite neighborhoods are contributing factors to what is impacting disabled Rochesterians. We encourage folk to read these reports and learn about the history of redlining and we will discuss the impact on disabled people in Rochester in other sections. Our point is this: disability is not separate from race and ableism is a compounding factor to what has already been well studied in Rochester.

As is well documented in our 2017 report, *Wage Disparities*, and our 2018 report, *Employment Barriers*, education and employment outcomes are linked. So, let's talk about this journey for disabled individuals. It is important to note that low educational attainment in Rochester is generational. Many Rochester scholars point to the decline in our educational outcomes to the changes made in the 90s. Beginning with the underfunding of IDEA, loss of school choice, No Child Left Behind all lead to schools and funding being tied to performance negatively impacted disabled children. Even the rise of charter schools has led to the exclusion of disabled students who cannot perform to meet metrics without additional supports. During this time, changes in Medicaid billing/reimbursement also impacted services for all disabled people by changing what therapies (and for how long) as well as assistive devices would be funded or not. And that these changes have had a lasting impact to this day. It is important to note that before these changes, Rochester boasted some of the best schools in the region, on par with its suburban counterparts. However, as is well documented in our community, these changes, which coincided with other societal issues, led to RCSD's current state.[12,13]

Currently, the community is reeling over the resignation of a beloved superintendent from the school district.[14] Consistent turnover of superintendents, multiple changes to school curricula, and turnover in special education department over the years has impacted disabled students. Unlike their suburban counterparts, city parents and guardians do not have as much of a say in the school budget or curriculums. Still, this turnover and lack of consistency are also taxing on city parents, guardians and students. Organizations such as the Children's Agenda/Roc the Future and the Childcare Council have developed strategies to help improve outcomes for Rochester Children.

> "We can't keep putting the blame on the superintendents but really need to look at our school system. This is not ok for our kids." – Rochester community member

Education Summary

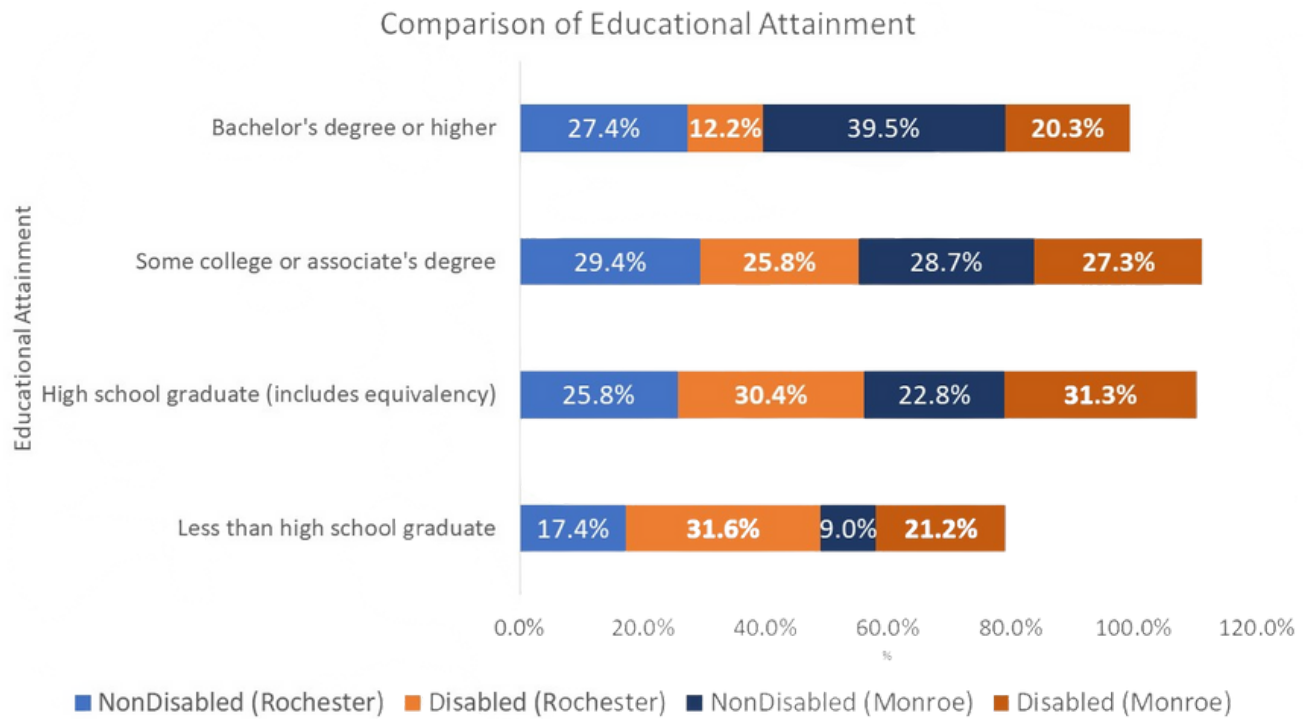## Comparison of Educational Attainment

Figure 4. Educational attainment for disabled and nondisabled persons in Rochester and Monroe County. Source: U.S. Census Bureau, 2016-2020 American Community Survey 5-Year Estimates

Overall, the educational attainment of disabled people versus their nondisabled counterparts is a startling comparison. Nondisabled people in Monroe County have the highest educational attainment rate of a Bachelor's degree or higher at 39.5%, coming in second at that same level are nondisabled Rochestarians at 27.4%. Only 12.2% of disabled Rochesterians have a Bachelor's degree or higher. The majority of disabled people in Rochester have a High School graduate degree or less with a combined total of 62%. Lack of educational attainment impacts the ability to earn higher wages and employment. In the following sections we identify some of the factors leading to barriers in education for K through 12 to the collegiate level.

Image Description: iStock image of an Asian presenting child painting with colorful paints

Education: Day Care/Early Childhood Education & Intervention Services

Early childhood education & intervention can be critical for disabled children. However, Rochester and Monroe County have experienced funding issues and shortages of workers even before COVID, and RCSD had identified these shortages early on in their Path Forward analysis in 2017/18. Additionally, many services are not co-located within areas where disabled children live. Co-located services have long been a best practice; it is a way of designing cities so people can get most of their needs within the neighborhood. Due to divestment in our predominantly Black neighborhoods as a result of redlining, these resources are not available. Food deserts are a prime example, but education is also impacted. As was referenced in our 2018 report, national studies show that for many children of color, disability is not diagnosed until later in life or misinterpreted as behavioral issues, meaning that they are often put into the school to prison pipeline, rather than receive services the family needs. Additionally, getting access to screenings might not be possible due to barriers on families highlighted in previous reports by The Children's Institute, RCSD and other agencies in Rochester. The Child Care Council is positioning itself to help the unique needs of disabled children.

Additionally, according to Jenn Bideman and Bethany Williams from the Childcare Council, screenings for disabilities such as autism have increased thanks to mobile units called the Grow Bus, hence the need for services has increased. Still, continued shortages, policy and attitudinal barriers mean disabled children are expelled from daycare/universal pre-k classes.

> **" black children with disabilities are expelled 3x more than white children. "**

Williams states, "On average, black children with disabilities are expelled three times more than white children. The families that we have worked with specifically, have been expelled at least two times. Unfortunately, we anticipate that it will increase in expulsions during the summer months, due to the lack of available childcare slots for full-time care, cost of care, and resources to support children with disabilities in camps and other summer programs. In addition, some summer programs go on more field trips and are less structured, which in turn, creates situations where there is a lack of consistency and routines and can lead to challenging behaviors. Unfortunately, that can lead to suspensions and expulsions."

The mobile units for screenings were a good solution to helping with the late diagnosis issue, but Bideman and Williams state that the shortages to meet those needs still has to be addressed. Bideman says, "But essentially, what we've learned is that across the board, early intervention services have gone up due to the pandemic, across the board--across the whole region. The majority of those requests are speech pathology. Before the pandemic, we already had scarcity in the early intervention workforce. And what was happening is we have heard stories of [...] early intervention professionals who are predominantly white, white women, were selecting zip codes that they wanted to work in and so they were intentionally not selecting zip codes in the city.

Bideman continues on the impact of these shortages, "And so you have all of these great things happening across the community, like the Grow bus of like doing all these screenings, right, except we don't actually have the services for the screenings. So you can screen everybody till the cows come home. But at the end of the day, if they're not getting the appropriate service to help to support that child, then what's, what's gonna happen, right, like they just continue to not have that support."

Bideman is highlighting a systemic issue: there is a need for more Black and nonwhite people to go to school for these areas and improve hiring and retention practices for current candidates. For example, RCSD's Path Forward identified a critical need for native bilingual Spanish/English speech pathologists for students coming in from Venezuela. Still, they were difficult to recruit due to competing needs from other cities and a low candidate pool. This example points to the long-term impacts of racism and ableism that we do not have a strong, culturally diverse candidate pool to serve the needs of our children.

There's tension between parent groups, disabled advocates and service providers on what types of early childhood education are best for disabled children. Often curriculum does not include a disability identity/culturally competent focus. Bideman confirms this lack of disability cultural competency by saying, "...I highly doubt in the childcare realm that you would see appropriate training for staff in inclusion for folks with disabilities. And that's not to say that there aren't like bright spots of folks that aren't doing it [...] But I don't think it exists."

For many people with certain disabilities, like autism, the types of early childhood interventions, like ABA therapy, have been deemed inhumane by organizations such as the Autism Self Advocacy Network.

Furthermore, Black autistic advocate and parent of autistic children, Tiffany states that it is important to understand nuance in this debate "if you don't understand how insurance, daycare for Disabled kids, and behavior issues that threaten the family unit are huge forces then you have the privilege of not having to make those harsh choices even knowing the potential for harm"

Further compounding the issue is that this is not a Black/White issue, even though data presents this way. Rochester as a sanctuary city receives many immigrants/refugees who have family members who are disabled and they too can be restricted in decision making not just on insurance but cultural values. Seeking services and care can be a complicated process for many families, let alone those with complex care needs, which Bideman confirmed by stating, "I am a cisgendered, ablebodied, mom with a college education and I do this work! It was difficult for me when I was looking for care for my child. It is an unfair system for so many!'

Further highlighting the needs gap versus availability, according to the ACT Rochester data, the overall public assistance approval rate was 24%. Bideman and Williams confirm that the high rate of disabled children cycling in and out of childcare programs is due to providers not having the proper skills, policy and attitudinal barriers, and staff to address the needs of disabled children.

Educational attainment:
K-12

We continue to see the same issues stated in early childhood intervention throughout the K-12 system, which compounds barriers towards this journey to employment. There has been a myriad of reports since 2017 by the Children's Agenda, and the Distinguished Educator from the State, highlighting the dire state of Special Education for city children. In 2020, a global pandemic and a state takeover only compounded these issues.

In an article on the state of special education in RCSD, Cheryl Carleton, the mother of a child with Down syndrome and president of the Special Education Parent Advisory Council in an article on the issues of Special Education, said "The special education department has really gone very silent.[17] And that's unusual for us. SEPAC has built a pretty good relationship with them." During our emotional emancipation circles of 2020, parents of disabled children reported high stress levels.

"We get no help. How am I supposed to work from home, school at home, help with the kids AND keep up with the therapies by myself? I'm a single mother! I'm exhausted and they don't care. He doesn't understand why he can't go to school." – parent of a disabled child

While the community dialogue during lockdown was around the emotional needs/learning loss of nondisabled children, the needs of disabled RCSD students were not fully addressed. Nor was a community-wide plan developed to support parents of disabled students. It is important to note, concerns of learning loss for disabled children was not unique to Rochester. A federal ruling has urged districts across the nation to make up for learning loss during the pandemic. Additionally, a series of missteps and omissions, such as investigations into falsified documents and the loss of the Director of Special Education, led to disparities in services for disabled children.[18]

These are heavy obstacles to overcome but point to the need for greater collaboration between the district, parents/guardians, advocates and organizations such as the Childcare Council and the Children's Agenda

Community members we spoke with feel the Rochester community has not developed a concrete support plan across agencies and organizations to help parents of disabled students.

In 2021 the district announced that School 29 was closed with no clear plan communicated to the community. School 29 had comprehensive PT/OT facilities, which none of the other schools have that level of access. This has led to some confusion in the community as they are unsure where their children can get these same services; not all schools in RCSD offer this level of comprehensive facilities.

"You're sending them to do what? What other school has a therapy room? What about quality therapy? And what's the plan?" – Rochester community member interview

Additionally, while observing several special education classes in 2019 for the Leadership in Education of Neurodevelopmental Disabilities (LEND) program, students were not capable of even the most basic of job skills and many were deemed "ready to graduate." To be fair, this echoes the concerns the community has had over the years about the college readiness of RCSD students (as well as ongoing debates on what college readiness means when factoring in racism, ableism, etc). A community-wide discussion also needs to include the voices of those who are most impacted.

According to NYS education data, as of August 2021, 51% of disabled students graduated overall, 1% graduated with a Regents with Advanced Designation, 49% with a Regents diploma, 1% with a local diploma, 3% with a nondiplomat credential, 33% are still enrolled and 12% dropped out. Rochester leadership and community have an opportunity to serve its disabled youth and build accountability with parents and students.

Policy & Other Recommendations

- Full support for ROC the Future with the following additions:
  - Increase number of BIPOC disabled advocates involved in skills training groups
  - Increased training (with funding) to help increase participation in summer learning programs
  - Disability related books for the Rosie the Reader program

- Build coalition with parents of disabled children and trusted BIPOC disabled activists
- Follow the recommendations by https://xminds.org/Nonspeaking-Autistics and ASAN

Educational attainment: College/University

Transitioning from high school to college can be tricky for many disabled students. Transitional services like vocational rehab are introduced late, junior year, when longer-term planning is needed. Several years ago, New York State introduced an alternative diploma (CDOS) where students would be required to do on-the-job training, but as of this writing, data requests on how that translated to actual jobs were not provided.[19]

Additionally, even if there was a goal of going to college there is no real good way to address and assess accessibility from all different aspects of a college until enrollment in that institution. Accessibility varies by disability and person, which gives an additional layer of complexity. With Medicaid not being transferrable state to state/the quality and availability of support services also vary by state/county/city therefore further restricting where a disabled student can go to college. Moreover, we looked at programs that offered students in high school tours of college campuses and it was unclear, across the board, how they managed accessibility. When speaking with our focus groups, overwhelmingly, the response was "we figured it out when we got there as we couldn't find the information we needed."

The added complexity of COVID did not necessarily lead to more accessibility. Many students went to Twitter to express their frustrations that accommodations such as remote classrooms were not honored and they had to drop out. This author also heard from local students expressing similar frustrations. Still, when the pandemic happened, these requests for online instruction, once a luxury, were accommodated quickly. Locally, colleges and universities followed the same pattern of online instruction with an unprecedented level of access. However, with the push for in-classroom instruction, it is unclear how individual instructors or institutions are maintaining that level of access.

Additionally, this author's students had difficulty getting their accommodations for online instruction during lockdown and did not receive them until the last two weeks of class. These students already had accommodations but the university was not prepared for such accommodations to be switched to online instruction.

A case where blind students sued the Los Angeles Community College District for lack of access to course materials highlights attitudinal barriers to access as the college repeatedly appealed the case after they lost the suit several times was recently settled.[20] Knowing what is happening in our country at other institutions helps inform advocacy locally. This and other cases speak to how institutions will fight these decisions in court rather than provide access so students can participate in higher education equitably. This author spoke on the complexities of obtaining reasonable accommodations via public video & private discussion and many disabled students left comments on their experiences:

- "Not only was it hard to get accommodations at my college, but it was downstairs & literally not accessible. Def got bullied by professors"
- "My accommodations said I was supposed to have a reader on exams but my school 'didn't do that' so I didn't get one and my grades suffered"

It also does not follow that COVID lead to greater awareness, and follow through, for increased accessibility on campuses. "One of my lecturers stopped streaming lectures online because he felt too many people were watching it from home instead of coming in person."

With COVID being an ongoing issue, we need to address the multimodal ways of learning that benefit many disabled students. These discussions on access in higher education mean that students are restricted in choice due to the additional barrier of ableism on top of socioeconomic barriers.

Total & Permanent Disability Discharge

"I got a letter saying that because I didn't respond to an attempt to opt out of the program, they automatically assumed I wanted to be enrolled. As long as you're with Social security they do this. I never received the first letter. I am in school getting my bachelor's and it has only been one semester! They said I can't take any more loans out for five years after they were discharged. How does this help anyone? I have to make several calls as nobody told my school! They did this without my consent, messed up my financial aid AND there's extra paperwork! It's indicative of an ableist system that says disabled people cannot make their own decisions. I have no say in this process. " --disbaled student

This program was created by the Obama administration to help disabled people obtain student loan forgiveness and help obtain employment. It was updated in 2021 to enroll those receiving SSA benefits, but restrictive requirements and income thresholds still apply but also do not exist for the other forgiveness programs. To find out more visit https://disabilitydischarge.com/forms

Policy & Other Recommendations

The Children's Agenda has proposed a few recommendations for RCSD:

- Align continuum of services: Programs and services for students in special education should be available in as many school buildings as possible so that students don't have to change schools.
- Mandatory professional development & support: Every school staff person who works with students with individualized education plans should have mandated proper training to support those students, along with consistent support.
- Prevent suspensions: Schools should reduce suspensions of students with disabilities and they should have more prevention programs to help avoid suspensions.
- Furthermore, our reccommendation is for higher education to make immediate commitments to Section 504 of the Rehabilitation Act and ADA to ensure success of disabled students during and after college.

Image Description: a professor riding on a student with a power wheelchair's lap with students smiling

Housing

Housing is a critical factor in one's employment and education. However, as was reported in 2018, in the United States, less than one percent of housing is accessible for people with mobility disabilities. In Rochester, the majority of housing for disabled people that is accessible is HUD subsidized housing. And, like many east coast cities, the housing stock is older, making retrofitting more difficult for accessibility. A national review showed that most disabled individuals live in buildings built prior to 1990.[21]

Rochester has unique weather and garages and covered parking are a premium as there are additional fees. Housing especially designed for disabled people, like Andrews Terrace, do not have covered parking available. Add plowing and even getting to the street, especially with Census data showing around 60% of disabled people saying that they drive alone to work, means that accessing a vehicle through the winter will be next to impossible for anyone with a mobility device. It is a prime example of structural ableism in decision-making.

Image Description: iStock image of a light skinned Latina mom kissing her laughing child who has cerebral palsy on a blue couch

In 2018, in an attempt to make new builds accessible via visitability standards, Rochester passed a local ordinance.[22] What is visitability? It is a subset of universal design standards. According to the University of Buffalo IDEA Center: "Visitability is an affordable, sustainable and inclusive design approach for integrating basic accessibility features into all newly built homes and housing. Visitability is based on the conviction that inclusion of basic architectural access features in all new homes is a civil and human right and improves livability for all."[23] At the time of this writing, however, the impact of this legislation is unknown. New York State is also poised to pass a visitability tax credit.[24] But this could be inaccessible to disabled Rochesterians as it requires upfront cost to the disabled person/household. Looking back at our map, Figure 4, disabled people live in high poverty Census tracts. Additionally, Rochester has an aging housing stock, so retrofitting these areas might be a significant hardship for property owners. For renters, advocacy on making their apartments accessible is needed, but financial assistance would be beneficial. It took this author 6 years to obtain automatic door openers on key doors to access the garage and the street independently.

Calculators show that the average rent in Rochester is $830, the only way to have overall accessibility that accommodates most disabilities is with the luxury housing market. Average rents are increasing around the nation and Rochester is no different. When we assessed rents downtown where a majority of this housing is being built, many can spend upwards of $1200 - $1500 or more for a one-bedroom apartment.[25] This housing cliff can pose an impediment to employment. According to the National Disability Institute 2020 report, disabled people have an average of 28% higher cost of living. The transition to employment needs to be able to cover these costs.[26]

Policy & Other Recommendations

- Universal design standards to be applied to all housing in Rochester
- Grants/funding to bring buildings up to universal design standards
- Modifications funding/grants for renters/homeowners
- Policy that landlords cannot charge more than 30% of income for disabled persons earning less than $200,000/yr
- Increase income limit for STAR program for disabled homeowners

Transportation is another critical barrier to employment. Let's start with those who drive. According to the ACS, 59.9% of those with a disability drive alone, and 13.8% carpool (this can mean someone else drives). While this seems benign, it does not explain the hidden costs of driving for those who have mobility devices, like wheelchairs. The average cost of a van for disabled individuals is $40,000 to $100,000.[27] If someone were to require the assistance of vocational rehab, the policy states that a van must be within 5 years of the date of approval. Additionally, long-term usage of sedans and SUVs can lead to health issues such as rotator cuff damage, which can be weeks or months of recovery from surgery and years of chronic pain (all of which impact the ability to work).

Those reliant on others to drive them are limited by the availability of those to get them to work. This can create a barrier as the need to align schedules and consistency (what happens if that person is sick? Late?) may vary.

For vans, the lowered floor combined with the inclement weather experienced in the region can mean repairs are needed more frequently. Our interviews showed that van repairs can average $2000. Our interviews showed the average cost of van modifications can be $15,000 - $20,000 with folk not qualifying for vocational rehab. The National Highway Traffic Safety Administration puts the cost of modifications at $20,000 - $80,000[28, 29] indicating that those we interviewed might have foregone needed adaptations due to cost. In the event of an accident, our interviewees stated insurance often does not replace these modifications, leading to longer out-of-work time or, depending on the employer, termination if they cannot show up for work. The company policy of "must have reliable vehicle" can have a negative impact on disabled individuals. Additionally, the remote work option eased concerns for many disabled and many we spoke with feared mandates to return to work due to concern over their vehicle or obtaining a vehicle.

Paratransit/public transit is often left out of the transportation dialogue. Again Census data shows over 11% of disabled people in Rochester utilize these modes of transportation. Unfortunately, Rochester has been a car-driven culture as many jobs/entertainment/services are located in the suburbs due to the increased impacts of white flight, and redlining. Over the years, there have been numerous active transportation plans and RTS has made some improvements to paratransit but riders still experience issues. In winter, conditions are worse as many bus stops are not covered, meaning anyone with a mobility issue utilizing the bus cannot utilize these stops.

Policy & Other Recommendations

- Remove 5 year rule restriction from vocational rehab and expand funding eligibility requirements for purchasing/modifying vehicles
- Create a 2 tier paratransit system
- Employer level policies:
  - Remote work flexibility
  - Increased transportation bonus for disabled persons/include paratransit if giving bus passes

Healthcare

Healthcare is another critical barrier for inclusion in employment. For many people who are disabled and on SSI or under the poverty guidelines, they are often on Medicaid. While we'll address the other associated benefits in the social services section it's important to understand the thresholds within Medicaid that might drive decision-making as to whether one should become employed or not. Also, we need to understand that systemic ableism, racism, and sexism are also contributing factors in healthcare (whether access to or inclusion in).

For example, we know that for those who are from marginalized groups, cultural ethnic groups, diagnosis of autism, ADHD or a DD, or illnesses such as fibromyalgia are often delayed. As we mentioned previously in the section on education, autism and ADHD are often mistaken as behavioral issues that lead to an increase in out-of-class detention or suspension, which is tied to the school-to-prison pipeline.

For those reliant on attendant care, this is only available via Medicaid or Medicare, not private insurance. So, therefore, if you need these services, you must be able to maintain an income that qualifies you for these services. And often when it comes to benefits many people are discouraged from employment because they are told that they will lose their health care benefits, particularly Medicaid. We will go deeper into these thresholds in the Employment Section.

In an interview with one black family in Rochester, an individual who wanted to work, and had qualified for many jobs in the past, had to turn them down because his social worker stated that if he worked, he would lose his benefits. The social worker never informed the family about the Medicaid Buy-In program for Working Persons with Disabilities nor about special needs trusts or the ABLE act that would help them to better make decisions about his future employment

Interviews with many families and individuals' health care is a deciding factor when deciding whether they take a job or not. The Medicaid Buy-In Program for Working Persons with Disabilities has a threshold of over $68,988 for single individuals as well as almost $95,000 for married couples.

"I have a master's degree and I am constantly having to navigate whether I am under the thresholds. I have not taken promotions, even though I know I am qualified. Making sure I qualify for benefits feels like a full-time job in and of itself."

The clear benefits cliff is not helpful especially for those obtaining Master's degrees or a Ph.D. or doctorate who still might need attendant care but whose jobs might not qualify them for Medicaid or Medicare services.

Image Description:: from New Mobility magazine Description: Dr. Cheri Blauwet examining a patient from her wheelchair

Healthcare

Also, as previously mentioned, if one has to have multiple doctors' appointments and those doctor's appointments coincide with the business hours of one's new job, you might not be seen as a productive employee or be unwilling to take that job due to internal policies around PTO, flex time, FMLA and its qualifications, or the probationary period for new employees.

Additionally, even if you need private healthcare, the scope of policies available for employers is unclear and whether they cover critical services for disabled people. This type of in-depth information happens at new employee orientation, not at the interview or on the employer's website. Additionally, rules around mobility equipment (referred to by insurance as durable medical) and the coverage of this is variable from employer to employer as well as among the major insurance companies. This can result in lengthy calls for approval during normal business hours to obtain what is needed.

Participants also expressed frustration that Medicaid rules for in-home use only meant that it was difficult or nearly impossible to obtain the types of equipment that would help them at work. COVID has allowed for remote work that many in our focus group said was helpful to them. However, the push for policies to return to work, such as the recent announcement by Governor Kathy Hochul, has made folk wary of being able to maintain what has helped them at home.

Many also felt uncomfortable with the uplifting of the mask mandate which can put disabled people at greater risk of getting COVID. Long COVID participants also expressed discrimination on the job, and difficulties in obtaining social services, which we will address in the following section.

It is also imperative to keep in mind that all this is happening during a health care worker shortage for attendant care in which many are facing low wages. Due to the *Wage Disparities* report and the efforts of 1199 SEIU and other community groups the Rochester Monroe Anti-Poverty initiatives and associated employers did adopt the fight for 15 mandates.

Many disabled people have said that they have opted out of work through traditional employers as these barriers lead to their salary paying for the care they need. Essentially, being in poverty (on SSI) meant they could be on Medicaid and at least have their medical bills covered. Many spoke of foregoing needed operations, specialists' appointments, or medications due to their employer-sponsored insurance not covering what they needed.

Compounding this issue, as celebrated writer and Black disabled advocate Imani Barbarin recently pointed out on Twitter, doctor's offices/service providers have the same business hours as one's job. So, suppose we know that people of poverty/those with disabled children work two to three jobs. In that case, most work environments are not going to be supportive of multiple doctor's appointments either for the employee or their children or for them to take the time to be able to deal with insurance rules and regulations, follow up/managing of one's care.

- Change the threshold for the Medicaid buy-in program to be consistent with other states such as Iowa with an income cap of $400,000 (and no asset limit) to allow more people with disabilities to take advantage of the program
- Create a separate form for the Medicaid Buy-In program to allow for easier application with the yes option set until you explicitly opt-out.
    - Address Buy-In Program thresholds for small business owners
- Increase allowances for catheters and other products for non-Medicaid and Medicaid insurance this would be an aspect of universal healthcare
- Individual employers need to adopt the following:
    - Standardized full DME coverage for all policies in NYS
    - Explanation of benefits and full details of benefits included in the offer letter or employer websites
    - The state of PTO as well as probationary periods to be more accommodating for potential doctor visits and adopt a flex time to accommodate medical appointments

Social Services

Social services are another barrier that has been previously identified to employment. Supplemental Security Income (SSI) and SSDI have varying thresholds and qualifications. Supplemental Security Income is for those who have obtained their disability before the age of 26 years old. The definition of disability under the Social Security Administration is disabled and unable to work. The Red Book, the overarching book that details policies and programs available to those on SSI/SSDI, outlines various ways that disabled people can still maintain their benefits while gaining work experience, what came up in our interviews was many people did not know that the Red Book existed, social workers did not understand or know the Red Book existed.[31]

If the very people tasked with helping disabled people do not understand how they could be helped within the system, then it is no wonder that many people stay on Social Security for decades. Additionally, with some of the barriers that we have previously spoken about and highlighted in this paper, obtaining employment might be too difficult for many people and it is easier to stay within poverty rather than go through the hassle of moving through all these barriers. It is also important to note that just because one cannot work, it does not mean that they should be consigned to poverty. According to the Social Security Administration, SSI recipients who are single receive $841 and couples receive $1261.

Another caveat of Social Security is that for those on SSI there is not a clear path on how to transition off of benefits even with work incentive programs. For example, speaking with people who have transitioned off of SSI, all recount how they reported their new incomes but due to delays in processing, SSA workers not understanding and various other issues, their new wages were garnished by the Social Security Administration due to overpayment as they were continuing to receive their benefits while working over the threshold.

While there have been many proposed changes to Social Security, the current system still stands.[32, 33] Benefits remain the most confusing for individuals and providers. Many telling conflicting information, various levels of knowledge and expertise, and no one repository of correct information to help individuals. Many expressed not wanting to be on "the system" but employment presented worse and more challenging barriers.

Many would point to the existence of work incentive programs as a clear path off of social security, however, this is factually incorrect. On the Social Security Administration's website are several reports on the ineffectiveness of the work incentive program, Ticket to Work. The reports consistently showed the following:

- low participation rate of SSA recipients
- lack of oversight for the agencies designed to help people with their Ticket to Work
- confusion among participants about how employment impacts benefits

Additionally, there were disparities in who was able to obtain employment: blind/low vision people had the highest rates and those with higher support needs had lower rates. It was also unclear to the researchers if those who obtained employment through Ticket To Work would've obtained employment on their own.

It's also important to note that the way that Social Security Administration "sees" disability is problematic in and of itself. When you're on SSI/SSDI you're labeled as disabled and unable to work. And it seems that the underlying premise of the Social Security Administration is that disability is temporary but that is rarely the case. Additionally one's disability does not go away when they are employed. This can lead to issues when applying for the Medicaid Buy-In program where you would then have to go through a secondary process of evaluation with doctors who do not know you. It is a heavy paperwork process as they need to access all of your medical records and then you are assigned a new disability onset date if you are approved for the program. Meaning that if I were to apply and get approved in September of 2022 then that is the onset of my disability according to the Medicaid Buy-In program and not the original date of 1985. It also points to why ableism in the medical community can have compounding impacts. This could be a potential barrier. If there is not good documentation of your disability and diagnoses you might not qualify for the Buy-In program and therefore might not be eligible for the care that you need that is not covered by private insurance. Furthermore, to have a reasonable accommodation at work, medical documentation is needed.

The definition of being disabled and unable to work is also problematic from a data perspective. The definition can lead to this population being dismissed rather than being seen as a potential workforce if they so choose to go into employment. Our database shows a common theme where people have stated that disabled people cannot work and these attitudes might be stemming from the misleading definition from the Social Security Administration as well as biases within the community surrounding disabled people. We can also point to these attitudes that are rooted in capitalism/racism where one's value in society is dependent upon one's ability to produce. It's also important to know that even if you were disabled and unable to work this does not mean that you should be cosigned into abject poverty.

Long COVID patients are beginning to overwhelm the social security system and healthcare systems. Disabled advocates have declared that this will continue to be a trend across the nation. Locally, disabled people have spoken about longer wait times for appointments due to the influx of long COVID patients.

The varying thresholds and requirements for accessing social services have long been, from at least 2014, identified as issues in Rochester by RMAPI and the Systems Integration team and FLPPS (Finger Lakes Performing Provider System), but these barriers persist despite these programs.

Lastly, the SSA was invented in a time where attitudes around care were deeply rooted in racism and sexism (Black women were caregivers and housekeepers by trade, whereas white women were expected to be homemakers). Additionally, it was a time when ugly laws were still in effect and that all needs and care should be within the structure of the nuclear family and not community. With little change to the fundamental structures to the SSA and social change movements excluding disabled people, leads to the system we see today.

The lasting impacts include institutionalization, isolation, low employment rates, and low wages for home health aides. In the 2018 report and *Wage Disparities* report, we discussed the impact of these low wages on disabled people. In short, if you cannot get consistent reliable care, then your ability to maintain a job is severely impacted.

Policy & Other Recommendations

- The Social Security Administration should raise the income amount to liveable wage plus the 28% increased cost of living due to disability
- NYS increase allowance to SSI to create livable wage
- A clear path should be created for those who want to go into employment
- Clear training for social workers and other benefits advisors on the Red Book and the sociated ways that people can get off of disability
- Update the Red Book and create consistent thresholds for ALL policies for benefits/housing (e.g. if SSI goes up, then HUD/Medicaid qualifications must also be changed to be consistent with the changes)

Image Description: iStock image of a light skinned woman in a wheelchair writing on a whiteboard with an Asian man and White woman

Employment

And finally, we're at the final stage of this journey which has many loopholes and barriers along the way.

Within employment, barriers exist. Often it's not just about getting the job but about the path to get there and how to maintain and retain your position. First, let's look at the data!
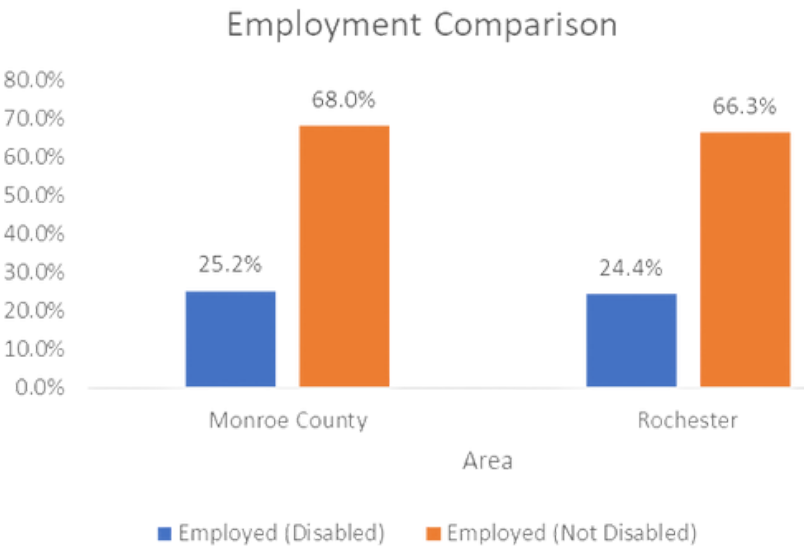

Employment Comparison

Figure 5. Employment Comparison for disabled and nondisabled people in Rochester and Monroe County. Disabled people in both the county and Rochester are employed at almost the same rate. Source: U.S. Census Bureau, 2016-2020 American Community Survey 5-Year Estimates

Compared to the 2018 report, employment has decreased for disabled people in the county from 33.3% to 25.2%. It is unknown why there was this significant decrease. Disabled Rochestarians also saw a decrease in employment from 25.3% to 24.4%.

The figure below shows the percent of workers with a disability by industry in Rochester. Additionally, it was calculated that the percentage of the overall workforce of disabled people in Rochester is 9%. If an industry has above 9% of disabled people it means that disabled people are overrepresented in that industry. It comes as no surprise that many are involved in some form of social services, health care retail, and the arts.

Looking closely at the industries for nondisabled people reveals more information. The Census does not give an exhaustive breakdown of these major categories for disabled people as they do nondisabled people. Retail and food services have an overrepresentation of disabled people and these fields have the lowest median earnings (around $21,000 and $18,000 respectively) as these do not require a college degree. Ironically, these fields were also deemed "essential workers" with a high risk of contracting COVID yet had the lowest median earnings. Let's look closer at the occupations within these industries.
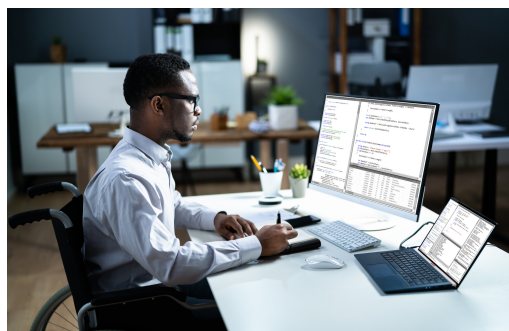

Image Description: iStock photo of a dark skinned Black man in a wheelchair at a laptop
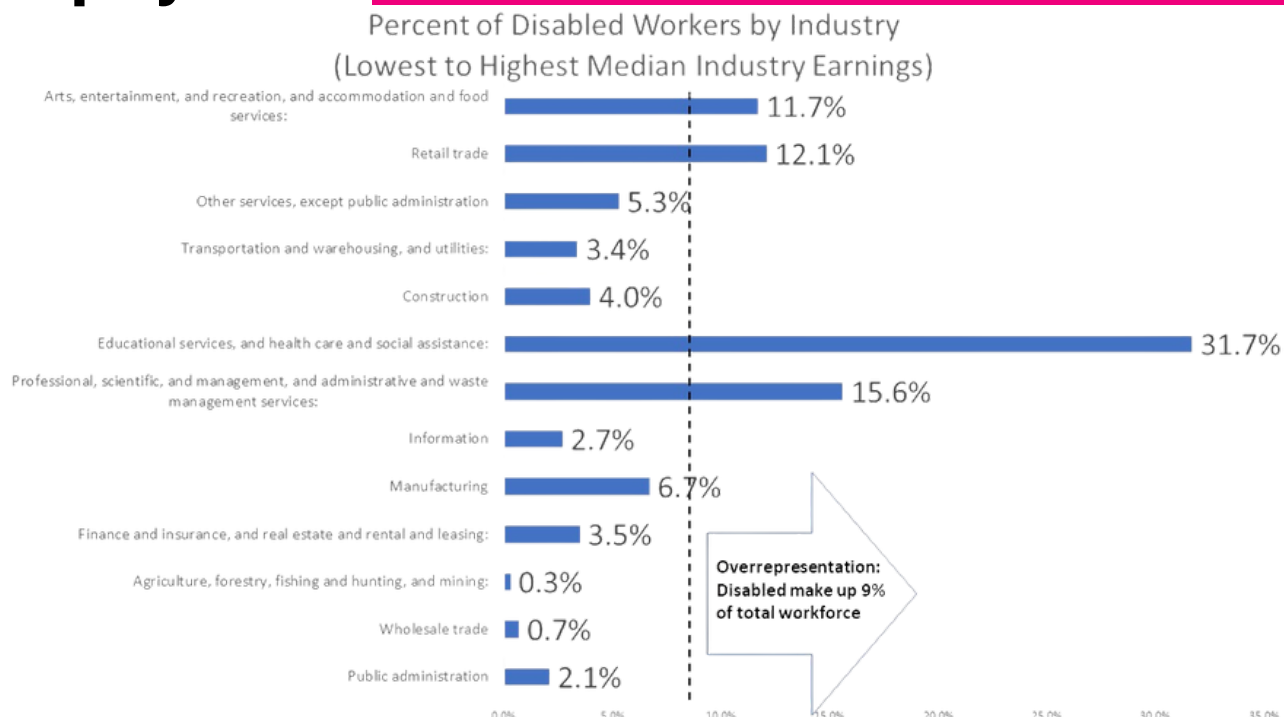
Employment

Figure 6. Overrepresentation of disabled people in top industries in Rochester. Source: U.S. Census Bureau, 2016-2020 American Community Survey 5-Year Estimates

The management category includes the computer, engineering, business, and finance occupations; all fields typically require higher degrees like a Bachelor's. For this category, the median earnings are around $48,500, placing them well below the threshold for the Buy-In program if they need attendant care. Service occupation gives more clarity to the previous figure as Food preparation has median earnings of around $16,000. It is also important to note that disabled people are overrepresented in occupations that by and large, require sitting/office work. Natural resources include farming/forestry, construction, and maintenance. These historically have been considered high-risk jobs, especially for Black men that can cause injuries, effectively taking them out of the workforce (or, after injury, pushing them into new lines of work).
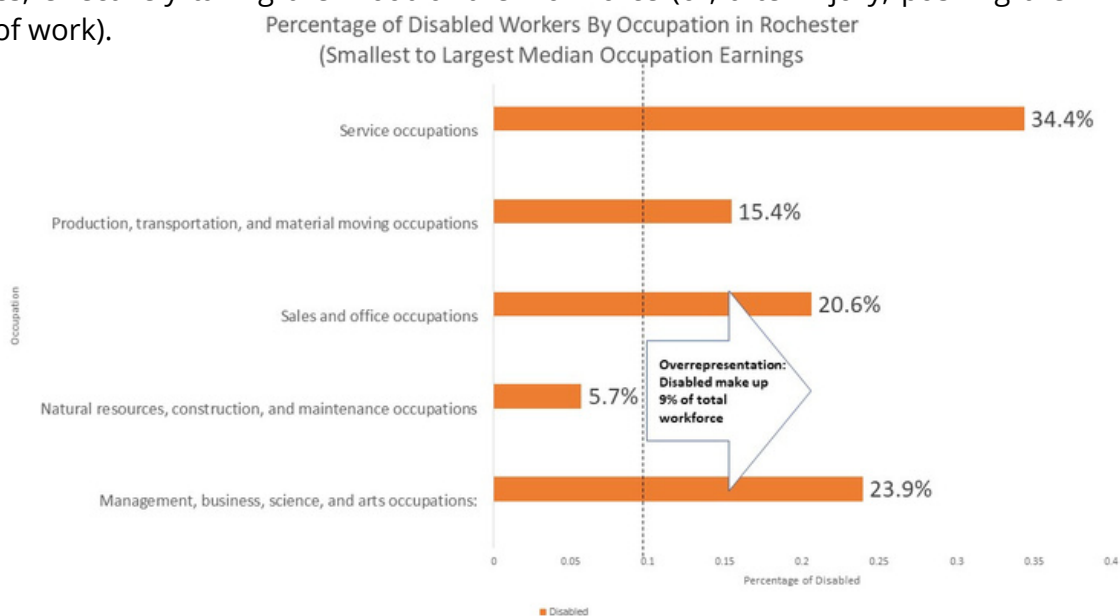

Figure 7. Disabled people are overrepresented in the lowest paying occupations of service (e.g. food service) Source: U.S. Census Bureau, 2016-2020 American Community Survey 5-Year Estimates

Employment

Ok, Let's use what we know and some additional employment data to make some strategic assumptions.

Earnings Comparison of Workers Ages 16+

Earnings	NonDisabled (Rochester)	Disabled (Rochester)	NonDisabled (Monroe)	Disabled (Monroe)
$75,000 or more	9.7%	5.5%	19.1%	8.6%
$50,000 to $74,999	14.8%	7.2%	18.9%	11.2%
$35,000 to $49,999	15.7%	10.7%	15.2%	10.2%
$25,000 to $34,999	16.2%	12.6%	12.4%	12.8%
$15,000 to $24,999	14.8%	16.9%	11.5%	14.6%
$5,000 to $14,999	17.0%	27.1%	12.7%	22.9%
$1 to $4,999 or less	11.7%	20.0%	10.0%	19.6%

Medicaid Buy-in Program threshold for single people: $68,988

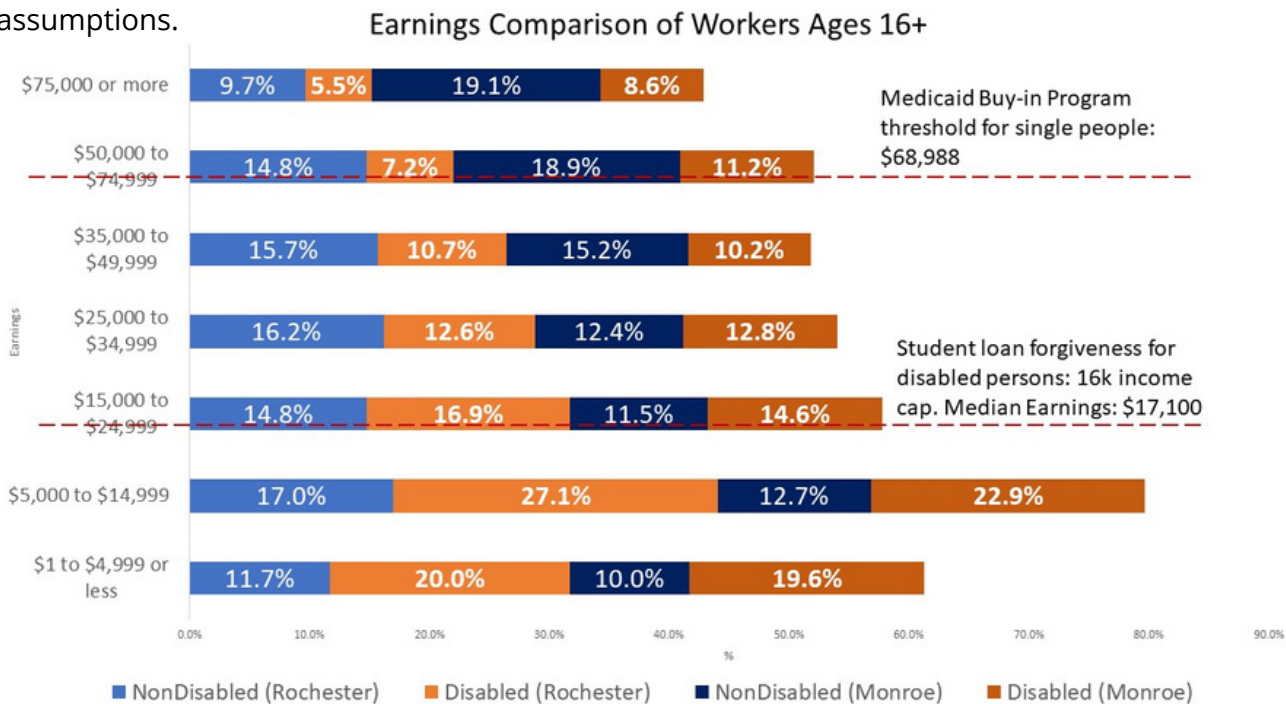Student loan forgiveness for disabled persons: 16k income cap. Median Earnings: $17,100

Figure 8. Earnings of workers 16+ in Rochester with Medicaid Buy-In and Student loan forgiveness thresholds Source: U.S. Census Bureau, 2016-2020 American Community Survey 5-Year Estimates.

The earnings of workers with disabilities are age 16 and up in Rochester are displayed in the above graph. Due to low educational attainment, the majority of workers with disabilities fall under 24,000 a year in earnings category. The previous figures show that 34.4% of disabled workers are in the service industry. Knowing the median earnings for this field are around $16,000, puts them at the income cutoff for student loan forgiveness. While there is no data for how many individuals in Rochester are utilizing this program, if they were, it effectively locks them into abject poverty to get the help they need.

Additionally, we see the majority of workers who are disabled are not reaching past the threshold of the Medicaid Buy-In Program, even though they might have the potential of doing so. This reinforces the need for the Policy & Other Recommendations in the Healthcare section that the Buy-In Program threshold needs to be changed to aid in the upward mobility of disabled people within the workforce. Not only are the barriers to obtaining higher education, and therefore higher earnings, at play but the disincentive of Medicaid thresholds to even obtain a higher education are a reality for many disabled people. The Wage Disparities report is still relevant here as wage discrimination based on race and sex is still prominent today, which are compounding factors (remember one can be Black, a woman AND disabled leading to lower earnings).

Prior to COVID-19, we know that 70% of reasonable accommodations for remote work that went into litigation were ruled in favor of the employer.[34] Like we saw in the education section about academic institutions quickly accommodating the needs of nondisabled people during a pandemic, we saw the same trends with employment. Suddenly Zoom became the norm.

Employment

However, as many speculate the reasoning is ableism and racism, mask mandates are being lifted and the urge from governors like Kathy Hochul to go back into the workplace many businesses are following suit. This is in addition to the Great Resignation where many quit their jobs as they did not want to return to a toxic work environment where systemic racism and ableism and low wages awaited them. Currently, depending on which employer, there are labor shortages and a simultaneous push for layoffs or forcing people to resign. As previously mentioned, the BLS survey overlaps with those in this paper as contributing factors for not being in the labor force. 70% of disabled Rochesterians were not in the labor force compared to 75% of all of those who are disabled in New York State who are not in the labor force.

While many disabled individuals stated that their productivity and comfort increase with work-from-home options, these returns to the office and lifting of mask mandates are seen as a threat to disabled people's health and employment. As previously stated in the healthcare section, the ability to have the accommodations in an environment that suited them led them to have more comfort and increased productivity. Regressive policies seem to be on the horizon. Employers also do not seem to be ready to create an overall remote work policy. Cornell University recently went under scrutiny in saying that they would not allow reasonable accommodations for remote work.

Disabled advocates on social media have earlier this year talked about the employment process itself particularly third-party apps that require applications, quizzes, etc that seemingly allow you to disclose your disability status. However, it seems that in a test of these apps and follow-up calls with the HR department, disabled applicants who disclosed did not have their resumes forwarded to the employer while those who did not disclose had their applications forwarded. There's long been discussion about the algorithmic biases that are brewed in systemic racism and sexism but this indicates that ableism is also a factor within the algorithm. Recently, the EEOC released a statement regarding discrimination based on these screenings and urged employers to not use these screenings. [35]

Why don't we see more disabled people in STEM?

In interviews with researcher Dr. Kristen Shinohara and other disabled STEM advocates, we discussed the barriers in academia that prevent disabled people and staff from obtaining their Ph.D.s or dropping out of their programs. [36] Some of the barriers are listed below:

- Lack of accessibility within the lab
- Difficulty in getting accommodations at their current institution
- Fear of the unknown about getting accommodations at other institutions, meaning that they cannot move from postdocs to postdoc or grant to grant across the United States like their nondisabled counterparts
- Medicaid is not transferable so therefore if they need attendant care they would not be able to get it in a new state
- Fear of judgment when assistive technology fails
- Judgment from their principal investigator but when assisted technology fails it is a personal failure and a moral failure on the disabled individual
- Lack of assistive tech that meets the needs of the disabled scientists

Image description: Reuters file image of Professor Stephen Hawking

Dr Shinohara's work is in line with what we have outlined in this paper and that concerns about housing, benefits, and societal attitudes towards disability impact the ability to be successful in a Ph.D. program.

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Employment

Additionally, job descriptions have long been a place where employers can discriminate in the hiring process by having ableist qualifications. In the now defunct Disability Visibility Project Facebook group there was a poll about the reasonable accommodations process once people were hired. The majority of respondents said that their job titles were changed and their position removed once they stated that they needed a reasonable accommodation and therefore they were no longer employed. A few weeks later, they found out that the job title was back up on job sites. Disclosure is a huge point of contention for many disabled people, especially for those with invisible disabilities for these very reasons. The World Institute on Disability published a graphic that said 50% of CEOs had some sort of disability but did not disclose them. If the very head of the organization does not feel comfortable with disclosing their disability status, what does that mean for those underneath?

The reasonable accommodations process in and of itself shows the inequity of a business; it is a poor attempt at fitting a person into an inequitable organization. From our interviews and experience as a former ADA coordinator, there's a tension in the field about compliance versus useability. Just because something is ADA compliant, doesn't mean that it is useful for those who are disabled. See the What Works section on how this author resolved this. Lack of understanding how a reasonable accommodation can be an asset, and not "special treatment", could lead to discrimination in the process in an attempt at micromanaging a disability rather than uplifting the disability and giving a foundation for success at the job. At a recent webinar for ADA coordinators, lecturers only discussed compliance and disregarded useability and the end user as necessary components to the job and disabled advocates in the room were shocked and dismayed. They felt that those who were charged with upholding the law geared towards the disabled should center the experience of disabled people when upholding that law.[37]

Let's also loop back to the Social Services and Benefits to also address who is being employed. Because of the barriers we've addressed thus far and going with what the SSA has determined, the bulk of disabled workers are those with lower support needs and those who are Black have lower employment rates and pay just like their nondisabled peers. Additionally, programs designed to help those who are disabled to become employed, would favor lower support needs individuals.

Attitudes in the workplace

A report on women with disabilities by *Lean In* in the workplace stated that they faced: [38]
- Increased microaggressions
- Not prioritized in DEI efforts
- Penalized for working flexible hours/remote work (2x as likely to say doing so hurt their careers)

In addition to this report Black Autistic TikTokkers spoke about not knowing the unwritten rules at work led to increased stress and disciplinary actions against them. They felt that their supervisors were not supportive and saw their disability as a problem. Black disabled women we interviewed also spoke of how they were denied promotions due to "being incapable" or had their expertise questioned.

Image description: adobe iStock of a woman in a hijab signing help in SL

Policy & Other Recommendations

- Capital investment grants for ADA accommodations especially for small businesses with 50 or fewer employees
- Creation of budgets for assistive tech device
- Adoption of work-from-home policies that best accommodate those who might need them
- Increase useage of 55 a-c and schedule A letters for civil service jobs at local and federal levels
- Prioritize disability justice in DEI efforts with experts in disability justice

This report highlights the myriad of barriers on the path to maintaining employment and gaining employment. As you can see the conclusions are self-evident: that there are inherent policy and socioeconomic barriers to gainful employment being attained by disabled people within the Rochester community, particularly when it comes to those who have multiple identities of having various ethnic backgrounds, various disabilities, and their gender identity.

In the current political and economic climate, the barriers are exacerbated by the world still dealing with an ongoing global pandemic. Traditionally, employment has only been seen as a linear path from education to employment, but this report highlights that many factors are involved. We also see three distinct categories based on how one can navigate through these barriers: abject poverty/SSI/SSDI, poverty/working poor, working and self-sufficient. We would be remiss in not mentioning that some are not in the labor force but are dependent on a spouse/family and not poor.

In the past, initiatives and nonprofits have heavily focused on teaching disabled people how to navigate these barriers but the data and anecdotes from our focus group suggest that a heavy shift is needed toward eliminating these barriers by changing the policies and attitudes that lead to the creation of the barriers. This follows what we see happening in the DEI space: that the focus is not on the marginalized person but the environment causing the marginalization. This is not to say that training focused on the disabled is not needed but should be reframed: if we give the supports disabled people need and uplift their strengths and change the barriers, then we will see disabled people living to their potential. This takes a community effort.

We are responsible to millions of Americans, and because of the extraordinary influence of our culture, to hundreds of millions of people with disabilities throughout the world in this and future generations. We are responsible to human beings who are forced to exist in conditions to which we would not subject our pet dogs and cats. We are responsible to potentially proud, productive people who are jobless, homeless penniless and hopeless. We are responsible to hundreds of thousands who die years and decades before their time. [...] Our problems are complex. We are confronted by a vast, inflexible federal system which, like the society it represents, still contains a significant proportion of individuals who have not yet overcome obsolete, paternalistic attitudes about disability and, indeed, about government itself. -- Justin Dart, Fmr Commissioner, Rehabilitation Services Administration, statement of conscious to the oversight hearing on the Rehabilitation Services Administration held by the Select Education Subcommittee of the House Committee on Education and Labor, November 18, 1987.

What Works

Jeiri Flores

At SUNY Brockport I had a professor who had me do assignments in alternative formats. She knew writing was difficult for me. I was able to do the assignment in a way that was best for me. A lot of the time we want to fit people into boxes and not let them show how they know the information.

I always tell people that I am different and worthy!

Image description: A light skinned Afro-Latina in olive jacket with a scarf and black glasses smiling the camera

Keith Jones

Image description: A hospital style black wheelchair with a golden Emmy on the seat. Text reads Krip Hop Nation, It's More than music

What worked was developing my own lane. I knew early on that I wanted to be an aeronautical engineer but they weren't going to let this kid from BOCES in. I was the first Black disabled kid in my school to be "mainstreamed." I told my aunt, "It aint like I can get up and go flip burgers at Burger King, I gotta make it happen some kind of way." We created an international, cross-cultural brand supporting disabled artists. I've got two Emmys as a result of community and this path we created over 20 years ago. It also was community support that helped me get to where I am. My core group has uplifted me and put my name in places I couldn't access. The vast majority of jobs come from personal connections or ties to have your foot in the door; it's not about what you know but *who* you know. If you come out of BOCES, they not checking for you. For me, it was turning my dreams into a business.

What Works

Anita Cameron

An example of what worked is when I worked for Andersen Windows back in 1995. I was using my wheelchair full time. They asked were there any accommodations I needed. They cheerfully did every one - put my desk on bricks so my wheelchair could fit, break down the work manuals to a size that I could pick up, allow me to be in a quiet, dark room after a seizure and move the microwave in the break room to where I could reach it.

When I went there for my second degree, Community College of Denver was the most accessible campus I've been on. About half of the students who went there were disabled. All campus shuttles were wheelchair accessible. My audiobooks, tapes and large print materials were available to me before the start of the semester. Most instructors had written in the syllabus encouraging students to let them know access needs.

One semester, I had a meeting with my speech instructor and the dean of the department, who wrote the text for my class, because they were telling blind students to look at their audience, and wheelchair users to stand straight. I explained to them that they needed to take into account disabled students and adjust accordingly. They listened to me and implemented my suggestions. Oh, and I got an A+ in the class.

My instructors allowed me to email my assignments to them when my wheelchair was busted or if I missed class due to seizures. They accommodated me in every way, and I was able to maintain a 4.0 GPA.

Image description: A chocolate skinned Black woman with long locs and a red shirt

Luticha Andre Doucette

I can think of a few things that worked. RIT has a policy that to graduate you have to complete the work on your own. But the organic chemistry labs were not accessible. While there were plans to upgrade them, the ADA regulations were not enough. Gary, our stockroom manager, had identified this and helped advocate to get the plans changed. We co-created an adjustable height hood so I could safely perform the labs. If it wasn't for him and the support of the department, I wouldn't have been able to complete my degree.

Secondly, I was able to do research and work with Dr. Robert Osgood, Professor Jacobs, John Schull and Dr. Paul Craig. All are examples of principle investigators who are just invested in the education of students. They are kind, creative, and just love science. Dr. Craig's lab was like the island of misfit toys. We all were different, but our strengths were recognized and valued by him.

When I went into business it was to create a fully inclusive space where I didn't feel less than anyone. I don't need to ask permission or get pre-approval to take care of my body in the ways it needs. I'm about justice. So, I try to ensure nobody has to identify themselves as disabled but just be able to show up and take part of our services. This is *my* business. Any barriers to inclusion are ones I have created or overlooked and it is up to me to fix them.

Image description: A honey skinned Black femme in a pink and black wheelchair wearing a houndstooth top and pink pants with legs crossed

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