



111 Washington Avenue, Suite 101
Albany, NY 12210
(518) 427-1060 Voice & TTY
nysilc@nysilc.org
www.nysilc.org

Preface

This survey was designed to assess the level of awareness youth and young adults in New York State have regarding the services they can access, as well as to assess the degree and severity to which unmet needs, discrimination, and other problems exist. We had 118 respondents between the ages of 13 and 29, and responses came from every major region of the state. We only accepted responses that were actually from these youth and young adults (to the extent that we could verify), in order to ensure that this was the best possible snapshot of the current experiences of New York's youth/young adult perspective, a point of view that typically is not directly solicited about their experiences, with researchers and surveyors often asking their parents instead. We deliberately chose not to ask for parent input, in order to preserve the value of the input of our youth and young adult respondents.

The responses provided through this survey, while not a scientific study, yield a number of conclusions which activists in the youth rights and disability rights arenas have spoken about for years, and suggest a number of dire occurrences that are still being ignored to this day. A few of these findings and conclusions are as follows:

75% of respondents aged 13-16 reported that they were bullied and/or discriminated against in school because of their disability status, and over 60% stated that the school did not resolve it appropriately. Given the recent passage of the Dignity for All Students Act, which specifically includes protections for students with disabilities, this is a clear indication that the statute is not being properly enforced. These youth are in a category that is at heightened risk for suicide, not by inherent virtue of their differences, but because they continue to be assaulted every day at school, whether physically or psychologically. Ignoring their legal protections, overlooking opportunities to educate and promote awareness about tolerance, diversity, disabilities, anti-bullying, and sweeping incidents "under the carpet" and "blaming the victim" is inexcusable until appropriate measures are in place and our schools and society witnesses a wide scale reversal in these trends. For around 20% of our respondents, their own families see their disability as a reason to abuse them further. They have few resources, and often, nobody will believe them when they seek help due to the combination of their age and disability status. Even if a component of their disability is an inability to lie, they will be ignored. If that wasn't enough, around 20% of the respondents who work or have worked encountered some inexcusable forms of discrimination that goes unaddressed like it is an accepted practice to harass the worker with a disability because of their perceived differences, with many telling tales that seem to fit better in a Dickens novel than in the 21st century.

A full review of Attachments I-III (the direct words of young adults with disabilities) indicates that a majority of the respondents have personally experienced discrimination and failures to accommodate which constitute violations of the Individuals with Disabilities in Education Act (IDEA) and Americans with Disabilities Act (ADA) at work, in school, and elsewhere. It also highlighted that many public facilities in New York State are still significantly out of compliance with the ADA's

standards for physical accessibility. With so many individuals having difficulty (directly and indirectly) not having their needs met, facing discrimination or being mistreated during the process, is the State, school districts, and local municipalities numb to the fact that they can be named as defendants in a lawsuit for the numerous violations alleged in this survey? It is also very likely that few of our respondents, were ever informed of their rights under the ADA, IDEA, or any of their corollaries derived from court rulings, especially since multiple respondents complained that their IEPs and 504 plans were completely ignored in school, and seemed to have no recourse whatsoever.

Specific data and results from the survey are presented in the following report.

New York State Independent Living Council (NYSILC)

2013 Young Adult Survey

NYSILC recently conducted an online survey of young adults with disabilities (ages 13-29) from across New York State. The online poll was a self-selected sample of young adults who responded via Survey Monkey during the last quarter of 2012. The sample included 118 individuals. Not every person responded to each question. Zip code identification indicated geographic distribution from across the State.

Demographics

In terms of demographics, the age range distribution of the respondents was as follows: Ages 13-16 (22%), Ages 17-20 (29%), Ages 21-24 (28%), Ages 25-28 (15%), and Age 29 (6%). Gender was slightly skewed toward males 57% to 43% for females. No other responses were received (transgender). Highest level of school or degree attainment included: Less than high school degree: 43%, High school degree or equivalent (GED): 34%, Some college but no degree: 10%, Associate's degree: 3%, Bachelor's degree: 6%, Graduate degree or higher: 4%. Race/ethnicity was reflected accordingly: White (83%), Black of African American (5%), Hispanic/Latino (5%), American Indian or Alaskan Native (2%), Asian (2%), Native Hawaiian or Pacifica Islander (1%), and Multi-Racial (2%). Last, for sexual orientation: Heterosexual/Straight/primarily attracted to other gender (83%), Bisexual/Pansexual/Omnisexual/attracted to multiple genders or without noticing gender (4%), Homosexual/Gay/primarily attracted to your own gender (4%), Asexual/Does not experience sexual attraction to others (3%), and None of the above (6%).

Awareness of Services

When asked, "Do you have health insurance at this time," 95% stated "Yes" and only 5% replied "No." About half of the respondents (49%) knew what an Independent Living center was. However, only 20% had actually received services from a center. 73% indicated that they receive services related to their disability at their school. 55% acknowledged that they receive services related to their disability at home. 29% receive services related to their disability at their work. 46% noted that there are other places that they receive services related to their disability.

33% identified that they've had issues when trying to get services at school. Another 26% stated it was not applicable because they don't attend school. 40% have issues when trying to get services at home. 11% note issues when trying to get services at work. Another 63% stated it was not applicable because they are currently unemployed. 35% have issues trying to services anywhere else. Individuals were asked to provide comments to describe some of the issues they faced. A sample of narrative responses included:

- My disability often gets in the way of me maintaining employment as employers aren't always fit to support my individual needs.
- People don't consider a learning disability to be something worth accommodating at work and school. When they find out I have one I usually get fired. Medicaid office refused to clarify info in the interview portion when I had delays in processing the info at the speed of their verbal speed talk. Then called security to escort me out and said I don't need to deal with people like you.
- All services on my IEP were not provided.
- Transportation issues and costs.

The complete set of responses to the survey question, "Please describe some of the issues you face when trying to get services (Q18)" can be found in Attachment I.

Un-met Needs

When asked to list any services or accommodations that they weren't getting, a sample of responses included:

- Not currently working. But in the past, explaining to my human resources manager that I was experiencing an episode and needed additional support, I was let go shortly after.
- I'm not getting disability or unemployment because they called me a problem...I didn't take in verbal info at their speed. Seizures will start again if I don't get Medicaid.
- Help getting a job. Help with financial aid for college. Help with individual living expenses.
- Academic tutor or 1:1 for college setting. Independent livings coach, social skills building group, assisted technology for college.
- Transportation.

The complete set of responses to the survey question, "Please list any services or accommodations you need that you aren't getting (Q19)," can be found in Attachment II.

A little more than half (54%) of the individuals indicated in a follow up question that they tried (but failed) to receive the services or accommodations described from the sample above. When asked to list any issues or challenges that they faced, a sample of responses included:

- My 504 plan is not honored by the school.
- The Disabilities Service Office and professors gave me a hard time when I requested testing modifications.
- Delays in responses, Medicaid issues, being on a waiting list, appointments for evaluations far into the future, being told "it's not in the budget."
- I utilize a Consolidated Services and Supports plan and there is not adequate available funding to meet the staffing needs required for 24/7 support.
- I have faced many challenges in trying to understand what I need alone. Then, getting teachers to change their lifelong teaching habits is difficult.

The complete set of responses to the survey question, "If you answered "YES" to the question before this (related to trying to receive services or accommodations), please describe some of the issues or challenges you faced in the space below (Q21)," can be found in Attachment III.

Discrimination

Individuals were asked, "Have you ever been bullied or mistreated in school by anyone because of your disability, or because you were seen as "different" for reasons that could be related

to your disability?" This covered things done by a student, a teacher, other workers at the school, even someone totally unrelated (such as another student's parent). A majority (58%) replied "Yes." Those that answered "yes" to the question, were asked if they felt that the school did enough to address the incident or incidents? 17% stated "Yes," but 43% responded "No," indicating that more needed to be done. The follow up question (to those who answered "No") asked them what they felt the school could/should have done differently. A sample of responses included:

- Their academic senate needs to form a student judicial affairs department to facilitate an impartial investigation on behalf of the student complaint as well as code of conduct violations. Accountability of the offenders is a low priority everywhere it seems.
- ...they should have investigated the incident that happened, get the parents involved with the bully, switch my classes, instead they just ignored the incident that happened.
- The school should have fired the teacher who bullied me.
- They could have not blamed me for "letting" it happen in the first place. They also could have actually done something more to punish the people who had bullied me.
- Disability awareness presentations or they could have placed me with a different teacher.
- Disability rights classes for ALL faculty, staff, administration, and students; Direct incorporation of disability issues in pre-existing anti-bullying initiatives, anti-discrimination initiatives.

The complete set of responses to the survey question, "If you answered no to the last question (do you think the school did enough to address the bullying incident), what do you think the school could/should have done differently (Q24)," can be found in Attachment IV.

When asked, "Have you ever been bullied, mistreated, or abused at home by anyone because of your disability, or because you were seen as "different" for reasons that could be related to your disability" by parents, siblings, other relatives, service providers, or anyone else who is in your home at the same time as you, and does something to you that they would not do, or would reconsider doing if you didn't have a disability or weren't "different" - 19% replied "Yes" to being abused at home. In a follow up question for those that answered "Yes," 18% were okay with how those situations were dealt with after they happened, 8% answered "No," indicating that they were not satisfied with how the situation was handled, while 74% stated that N/A because they were never hurt at home due to their disability. For those that answered "No" to the last question, they were asked what could have been done differently. A sample of response included:

- There needs to be easy access to attorneys and advocates because PTSD that results from ongoing mistreatment does not put anyone in the right place mentally to confront anything like this even for people w/o a disability. Why should people with disabilities be expected to handle double the emotional distress of the situations in progress?
- In the past, a teacher would provide ABA services incorrectly and punitively when I was 4. I would scream and bang my head every time she came, one of her ideas was to use hot mustard to teach me the difference (between yes and no)...so when I said yes I would get hot mustard. My mother said that was not okay. I am unable to explain what happened in the bedroom with the closed door but I screamed all the time and my mother thought I needed ABA and that even though it was aversive for a year, it must be good for me. Later she learned that if I was tantruming more than 2 weeks, the teacher was not doing it correctly. I actually regressed because my tantrums were rewarded with escape and I didn't have to work because I was screaming and crying throughout most of the sessions.
- They didn't see it as abuse they just felt that I was being too sensitive and they were just "jokes." I am ok with how it happened because I don't live with them anymore, and I am a stronger person because of it.

The complete set of responses to the survey question, “If you answered no to the last question (are you okay with how the situation was dealt with related to being abused at home), what do you feel should have been done differently (Q27),” can be found in Attachment V.

Last, when asked about being bullied or mistreated at work because of your disability, or because you were seen as "different" for reasons related to your disability by coworkers, supervisors, your boss, customers, clients, or anyone else that you could expect to deal with on your usual work shift, 11% responded “Yes,” 35% “No,” and 54% N/A because they never had a job or are currently unemployed. In a follow up question for those that answered “Yes,” 5% felt that their situation was dealt with fairly and appropriately, 9% felt “No” it was not handled correctly, 34% answered I was never bullied at work, and 52% replied N/A never had a job or currently unemployed. For those that answered “No” to the last question, they were asked what do you think should have been done instead. A sample of response included:

- My co-workers did not understand my disability and locked me in a freezer. My manager did nothing to them. One manager was good to me but he was not there all the time.
- The blame was placed on me and not the supervisor. The supervisor should have spoken directly to the one doing the bullying.
- They should have done an investigation. MY boss was docking my hours and when I reported it to his boss, they did nothing. I had the proof my time sheets and my pay stubs, and when I quit he gave me all the hours back that he had taken. I pointed this out it was black and white, and his bosses didn't do anything about it. I felt that they should have had a talk with him about it instead of just kicking me to the curb.

The complete set of responses to the survey question, “If you answered no to the last question (do you think the situation was dealt with fairly and appropriately related to bullying at work), what do you think should have been done instead (Q30),” can be found in Attachment VI.

Gender and Age Range Filters

The data sets were processed through Survey Monkey’s question filter for demographic questions related to gender and the five age ranges. Listed below are the most significant findings from both cross-tabulations.

When analyzing the data and gender trends:

- The question related to the highest level of education identified mixed outcomes from this sample. “Less than a high school degree” was 55% Male versus 29% Female, “High school degree or GED” was 29% Male to 41% Female, Some college but no degree was 8% Male to 12% Female, Associate’s degree was 0% Male to 6% Female, Bachelor’s degree was 3% Male to 10% Female, and Graduate degree or higher was 5% Male to 2% Female. Therefore, males in this sample experienced a gap earning a high school degree and working on various undergraduate degrees compared to females. The information doesn’t suggest a reason as to why.
- A question related to services or accommodations that young adults needed but were not getting were followed up by a question that asked if they tried to receive any of these services or accommodations. 59% of Males responded “Yes” they tried to receive these services or accommodations compared to 45% of Females. One possible conclusion for this increase could be that the increased number of males without a high school degree and “some college but no degree” could have created a necessity to pursue services for males. There is no information to assess the assertiveness of either males or females.
- For the follow up question to bullying at school asking if the school did enough to address the incident, only 10% of the Females responded “Yes” and “49%” said “No,” indicating that this

sample reflected a lower percentage satisfied with how the incidents were handled and a higher percentage dissatisfied with what was done compare to Males. There is no additional information to help clarify this difference.

When analyzing the data and age range trends:

- The question inquiring about health insurance coverage demonstrated a progressive spike for individuals in the upper age ranges, as they head toward the transitional cusp of adulthood when many are at risk of potentially losing health care. A total of 6 individuals identified that they did not have health insurance: (2) 17-20 years old, (1) 21-24 years old and (3) 25-28 years old. Based on the ratio of who had health insurance to those who did not, the 25-28 year old age range posted the highest rate at 18% for those uninsured. Individuals who were in this void will need to be informed about how to option coverage under the Affordable Care Act in 2014, Medicaid if they are income eligible, or their employer if they are working and the benefit is available.
- The question about being bullied or mistreated at school identified a significant response of 75% from the 13-16 age group. In the follow up question asking if the school did enough to address the incident, 14% replied "Yes" and 62% said "No" for the 13-16 age group? The 17-20 and 21-24 age groups reflected better satisfaction with how the school addressed the incident ("Yes" responses of 21% and 29%) and less dissatisfaction with how the school handled the situation ("No" responses of 38% and 36%). This same age range had the highest response to being bullied or mistreated at home, responding 33% "Yes." All other age groups fall off in terms of number and percentage responses (the closest number and percentage is half the amount identified for the 13-16 age group).
- The question related to being bullied or mistreated at work received the greatest response from the 25-28 age range with 31% saying "Yes," representing 5 individuals. The next relevant comparison would be the 21-24 age group with 13% response rate for 4 individuals. In the follow up question asking if the situation was dealt with fairly and appropriately, 8% said "Yes" while 25% replied "No." The 8% "Yes" reply was for only 1 person, while 7 of the 9 identified above felt it was not handled "fairly and appropriately."

Attachment I

Q18: Please describe some of the issues you face when trying to get services:

- I have had problems getting financial services for my college. I have had problems getting a one on one tutor for homework help. I have had problems getting employed. Not getting employed isn't helping me at all being with my confidence down at times. I am not at a level where I want to be at with my age.
- My disability often gets in the way of me maintaining employment as employers aren't always fit to support my individual needs.
- People don't consider a learning disability to be something worth accommodating at work and school. When they find out I have one I usually get fired. Medicaid office refused to clarify info in the interview portion when I had delays in processing the info at the speed of their verbal speed talk. Then called security to escort me out and said I don't need to deal with people like you.
- None
- Every time I try and apply for services they deny me. I have a hard time getting a job. I have memory problems with going to college. They don't help me enough in the college I am attending. I do feel I do need help getting myself better but there is nothing out there that is willing to help me out. I wish there is and wish I could get help but the only one that I applied to for me to get help in which I was denied was this thing called VESID. I did pass a test related to restaurant experience that I paid for myself to get into and I did get a job here and there but they didn't help me keep the job, instead they employed someone else and released me from the job. The professors also didn't help me in college in which I finally received counselor that helped me get a better grade since the professors didn't want to help me. I am trying to take another route around it and also wasn't getting enough money for me to attend college.
- None
- My parents have to fight to get my services at after school place. I'm an honors student so I can't leave class all day long. I get upset. DOE made my mom fight for 4 months to get my PT at the gym I've been going to since I was a little kid. In June I graduate and we don't know what I will get. Just went to one transition meeting and one eligibility meeting. Waiting to find out.
- Paper work wait, getting approval, no agency had room to take us.
- Transportation
- Some places won't take my parents insurance.
- I don't have a good case worker who is supposed to advocate on my behalf.
- No funding for programs.
- My parents are having a hard time with eligibility issues with the state.
- None
- Asperger's, OCD.
- Sometimes there is a shortage of meds in the pharmacy.
- None
- None
- Long waiting lists! Speech - took almost 2 years on waiting list - just started.
- Do not understand ACCES VR's role in job placement. I want to work. I'm trying, but it's hard.
- Trying to get help with getting in to college
- School will not allow the therapists to do assessments for DME like a stander or a new wheelchair, while I am aware of many, or most, schools that do this. The weight room at my school is inaccessible (up a few stairs) and there has been no attempt to accommodate.
- None
- People with abilities DO NOT EXIST
- None
- Continue to request speech therapy in the general education classroom not a segregated less challenging therapy room. District's response...'we don't do that at the high school'.
- None
- None really
- None available
- Not enough support services for college, no independent living skills or social skills groups available for at home, lack of medical providers dealing with adults with developmental disabilities
- Appropriately trained personnel on district school bus
- Traveling
- KEEP WAITING FOR STATE TO RELEASE FUNDS TO START INDEPENDENT LIVING IN A SUPPORTED APARTMENT. HOPING THAT APT WILL WORK OR WILL NEED GROUP HOME. WOULD LIKE A FAITH-BASED GROUP HOME EXPERIENCE AND SUPPORTED APARTMENT WILL BE TRIALED THAT WAY.
- Availability of services in the community, knowing what services are available, not fitting into a current pigeon hole 11/4/2012 12:02 AM
- Need to have all team members present a meetings
- People do not want to work with adolescents. They prefer children without challenging behaviors.
- I can't get anyone to my home to teach me life skills and mobility.
- None
- None
- Can't find or keep reliable staff through CSS
- I have fetal alcohol syndrome. I have a hard time in school learning.
- I am homeless and drink and do drugs. I need a place to live and a job.
- Need respite care both in and out of the home. I have waited 2 years for a residential/habilitation worker.
- My mom has to advocate for me because I do not understand what is happening and I get very anxious. I have fetal alcohol syndrome and have a hard time with relationships, money, judgment and caring for myself but I want to be out on my own.
- My mom is taking care of this for me but I am worried what will happen when I go to college.
- I have fetal alcohol Spectrum disorders and I am finding it hard to get services in the community to help me with budgeting, child care, etc.
- Transportation. I do not want to ride a special education bus so my parents have to transport me to school
- Currently in an RTF. Need CR
- Not enough challenging work, lack of recreational activities
- Help in getting a job
- Staffing shortages Transportation
- None

- School can be difficult to deal with CSE
- I receive assistance at home through CD-PAP (through the Monroe County Health Dept). The only issue that I have with these services is that the number of hours that I qualify for can change when I am reassessed every six months. I really need the support, so when my hours decrease, this can cause me difficulties.
- It can take a very long time to get the services - a year or more for residential/habilitation. There aren't enough openings for some services and a long line of people waiting for the service - supported employment, college courses, etc.
- Not enough support for behavioral challenges
- There is not enough funding to help me with everything I would like to do. I have a volunteer job and they are good to me but getting staff to go with me is hard
- Huge delays and always being told "funding/budget" issues...waiting lists that are 3-6 months long when services are needed immediately. Also delays in responses from agencies.
- Limited funding
- Lack of staff lack of understanding lack of transportation
- None
- None
- Eligibility.
- Necessary services and supports are not readily available. There are long waiting lists for quality services.
- Sometimes it takes a long time to get proper documentation for proof. Other times they don't believe I need certain service, when I actually do.
- I have been told that I'm not severe enough in my symptoms to warrant most services, and have been told this for most of my life.
- Not enough agencies offering services. Not enough caregivers at the agencies, due to cut backs in funding NYS has reduced services
- None
- None
- Difficulty to find providers and services
- None
- None
- Not a lot of people to do work at home due to living in a rural community
- None
- Trying to find a job Right now my services are okay, but last year it was months when I didn't have a mentor. Next year I turn 23 and I don't know if I will still have services.
- Whether the employer or school will pay for the accommodation were the agencies such as access VR. It is not necessarily whether the accommodation will be the build but who will fulfill it/pay for technology/other things etc.
- They keep putting me in regular classes with regular kids. I'm in 9th grade but can only read and do 4th grade math it makes me feel stupid. I want to be in a different school where I can learn something
- Needs academic support (outside of school). Resource is not always the best option.
- None
- A lot of professors want to help, but are incompetent or forgetful.
- Accommodations at Healthcare provider
- None.
- All services on my IEP were not provided
- None
- Transportation issues and costs.
- Frequently ignored, most common line given is "just trust us"

Attachment II

Q19: Please list any services or accommodations you need that you aren't getting:

- Trying to get employed.
- Not currently working. But in the past, explaining to my human resources manager that I was experiencing an episode and needed additional support, I was let go shortly after.
- I'm not getting disability or unemployment because no they called me a problem because I didn't take in verbal info at their speed. Y seizures will start again if I don't get Medicaid
- None
- Help getting a job. Help with financial aid for college. Help with individual living expenses.
- None
- Getting them all this year now
- None
- Transportation
- Resource centers that offer socialization services and therapy ABA.
- None
- Residential
- Services outside the home.
- None
- Extra time to complete work, extra copies of instructions from teachers, meetings with teachers
- None
- None
- Help with applying for and getting a job. Employment help and how to do interviews and applications.
- None
- My CCS plan doesn't pay for my college classes. I audit a class each semester to continue my learning and be a part of the college community.
- Extra help, extra time, calculator.
- None
- None
- I don't have any services
- IT'S WHAT IT'S IS
- None
- None
- Tutor, Reading Program
- Respite, transportation.
- Food Stamps and HEAP.
- I don't know. None I think.
- RESPITE
- Academic tutor or 1:1 for college setting. Independent livings coach, social skills building group, assisted technology for college 11/6/2012 7:53 AM
- Handicap accommodations at the Women's and Children's Hospital at Buffalo - no lifts, no wheelchair scales, no connection between buildings for those in wheelchairs.
- Transportation
- WILL NEED MORE RES/HAB AND CSS HOURS MOVING INTO APARTMENT & NEED FUNDING TO EXPAND CSS PLAN TO BE BOTH DAY AND RESIDENTIAL!!!! NEED ASAP BECAUSE LIVING WITH PARENTS IS NOT WORKING AND FAMILY RELATIONSHIP HAS GREATLY DETERIORATED!!!!
- Community based options for participation
- Ipod touch, ipad.
- Medical
- Not currently receiving community rehabilitation due to people not wanting to work with people my age.
- None
- None
- Staffing Socialization
- None
- An apartment
- Residential habilitation worker has not been found for me since 2010.
- One to one supervision in a living environment.
- None
- I process things slower than most people and my employer sometimes has a hard time with this. I also have a hard time budgeting my money, relationships, and get medical care. I have also been homeless 2 times in the last two years. My mother is taking care of my 2 year old. A church group has given me a place to live for a short time. I have a very hard time filing out the paperwork for services, like day care.
- None
- CR for living-wait lists More in home/community help, proper residential placement
- None
- Transportation
- None
- None
- Supported Employment in the community.
- None
- None
- Medication management with a psychiatrist, respite, OT, PT, not getting day hab that I wanted, transportation
- None
- None at the moment
- None

- None
- Help with skills at home.
- Residential Support Services and creative housing options that provide 24/7 support in my own home.
- Having test questions read to me
- None as of right now, other than finding a doctor's office that is (accessible).
- Independent living help. Housing placement of some kind
- Use of Internet at school- Wi-Fi. Use of aquatic servicers at school due to budget cuts.
- None at this time
- American Sign Language interpreters
- Support staff-aides, teachers, behavior analysts
- None
- None
- None
- Need a job in the automotive industry which will accommodate my disabilities. Transportation.
- None
- I'd like some help getting a job.
- None. Standing wheelchair, for more efficient standing so that I could be active in other areas and do therapy at the same time. Multitasking would allow me to do so much more rather than taking time out of my day just to stand and being able to do nothing else while I am. 10/25/2012 6:14 PM
- Adding, subtracting, reading
- Extra academic support outside the classroom.
- None
- None
- None
- Accessible scare at Healthcare provider
- None.
- Counseling, tutoring
- None
- Train fare discount. Handicapped parking in NYC. Vocational assistance.
- Use of word processor for exams

Attachment III

Q21: If you answered "YES" to the question before this (related to trying to receive services or accommodations), please describe some of the issues or challenges you faced in the space below:

- VESID
- Smaller organizations, particularly non-profits often treat my condition as a liability and do not offer support services.
- Just because my face doesn't look like down syndrome doesn't mean I'm making up a disability. I've even been accused of phony docs and was devastated by this accusation.
- They discriminated against me.
- Speech and Language
- Cost is too high and limited time of bus service
- My mom was told they only take Medicaid.
- I need full assistance with all my daily needs. Currently, the funding is not there for me to live other than with my parents.
- My parents have tried for me and have problems.
- My 504 plan is not honored by the school
- Not really sure where to go to look for jobs suitable for me. Lots of volunteering available but employment part time would be awesome
- The Disabilities Service Office and professors gave me a hard time when I requested testing modifications
- Trying to receive above service (see question 19)
- NO ONE LISTENS
- Lack of resources
- I do not receive enough money for the programs I listed.
- Ongoing denial of services through OPWDD. Applied for Home and Community Based Waiver.
- Agree but never fix anything.
- "We've got to wait until the State rolls out the new plan, so there's no reason to spend the time and money to rewrite her plan this year (Jan 2012)." "Now the State will be starting a new plan Sept 2012, so we need to wait until then to rewrite her plan to include funding for an apartment." "Oh, didn't you hear? The State has moved back the new plan rollout THREE times, and we don't have any idea when we will receive the training so we can rewrite her CSS plan." Blah, Blah, Blah, Blah.....WHAT IS UP, OPWDD
- Finding a group to participate with that is not center based day/hab
- MB later on when I have enough money
- Was denied
- Please see question 19.
- Meeting people
- I have addiction and mental health issues.
- Several, the pay is low for res/hab workers, the hours suck and I want to get out in the community
- There are no services for me. My mom has tried over and over again. She has pieced together some things for me so I can be safe. She has custody of my 18 month old son.
- I have a hard time understanding all the paperwork that is needed for things like day care for my son, getting Medicaid for him, leases, or a full time that has benefits. Right now I work two part time jobs and have to pay for benefits that I can't afford.
- Giving my bed away to someone else- county wanting more tests.
- Not available.
- No job openings available right now.
- There is not enough funding to go around
- Delays in responses, Medicaid issues, being on a waiting list, appointments for evaluations far into the future, being told "it's not in the budget"
- Not able to qualify for MSC--hard to get.
- I utilize a Consolidated Services and Supports plan and there is not adequate available funding to meet the staffing needs required for 24/7 support.
- Waiting for case meeting
- I have been told that I am not "bad" enough to warrant those services.
- Budget restraints for aqua therapy- due to changes in budget the school no longer can offer the service. Due to school restrictions they do not allow use of their Wi-Fi for school functions. I need to use my computer to communicate, do my homework on etc. and have to supply the service myself.
- Some doesn't want to be responsible for paying ASL interpreters and probably know nothing about ASL interpreters agencies for them to contact
- No people available, no funding source/money to pay for other than during school services, long wait lines for community recreation programs, overcrowding at special Olympics functions.
- I have everything I need. I "tried" and succeeded.
- I live in a rural area and even volunteer time is limited due to transportation issues.
- My mom makes all the contacts for me. I wish my agency would give me assistance with this. I'm also looking for volunteer opportunities.
- It is a matter of time/justification. Gaining this chair would allow me to work/study while also doing therapy instead of taking time away just to stand and neglecting my other responsibilities.
- I keep getting moved to the next grade and they cut the amount of work they give me
- I have faced many challenges in trying to understand what I need alone. Then, getting teachers to change their lifelong teaching habits is difficult.
- There isn't an accessible scare to use. It isn't feasible to get one at this time
- The service was not provided at school
- Bullying
- Trying to get to the necessary offices at the times required is difficult and expensive.
- Told that my documentation was too old to even begin requesting accommodations

Attachment IV

Q24: If you answered no to the last question (do you think the school did enough to address the bullying incident), what do you think the school could/should have done differently:

- Their academic senate needs to form a student judicial affairs department to facilitate an impartial investigation on behalf of the student complaint as well as code of conduct violations. Accountability of the offenders is a low priority everywhere it seems.
- It happened in the past, but they should have investigated the incident that happened, get the parents involved with the bully, switch my classes, instead they just ignored the incident that happened.
- Addressed it with the kids , punished them and /or called in their parents
- Followed up with complainants.
- The person bullying me didn't get in trouble until a teacher got them in trouble even though it was on camera. The principal doesn't care. He just pretends it doesn't happen.
- Watched to make sure it didn't happen again.
- Notified the other student's parents about the problem. I was told the principal would do that, but she never did
- Punished the students for bullying
- Pay attention
- The school should have fired the teacher who bullied me
- I be sad school be done
- STOP LOOK AND LISTEN AND MOST IMPORTANT REPORT THEE INCIDENT
- A letter of apology from the uneducated, uninformed, poorly trained 1:1 aide & bldg. principal; offer peer mentoring; don't tell me I can't take a foreign language because of my testing scores / alternate assessment placement. Until Tenure is no longer offered a teacher or school administrator in a K-12 school setting, change will be minimal. Tenure (a truly troubling terrifying term) in New York State needs to be addressed and until it is, the complacency in which those born with a disability are treated FAIR in an LRE are just words.
- More training on staff.
- NA
- They should have actually talked to the kids
- In the college setting, there is an ongoing ignorance with instructors on what autism is, and their inability to attempt to help. Administration doesn't address the needs of those with autism, and when presented ways for them to help, it was responded "it's not my problem".
- Sometimes I think the kids may be making fun of me but I don't know. I am scared to ask for help.
- Punished the other kid. They don't punish him so I get my revenge.
- I had a one to one aid all through school and in day treatment.
- I have a hard time running. I am always one of the last kids to finish running in gym class. Some of the kids make fun of me and the teacher doesn't do anything to stop them. My mom asked for a special gym class, but I can do the other things, just can't run fast. One gym etcher understands but the other ones don't.
- When I try to settle it myself the teacher hollers at me
- But all kids bully and they are sneaky
- Talked to the other student and explained how they were being a bully
- Adults need to be more watchful, and proactive.
- Provided more supervision so those incidents would not happen. Or, separate accommodations.
- The school needs to provide more training and/or not accept students it is not equipped to handle. Bullying, etc., was from professional staff at school.
- Disability awareness training attitude adjustments
- Not put 5 teenage girls into a room and leave them alone.
- Kept those students out of my classes.
- The school bullied its teachers to not to tell the truth during my hearing. They were not getting to the root of the problem, the bullies. They would just say they were kidding, so they get slapped on the wrist and sent back out with no consequences. Had to leave district with no help school had no reporting in place
- They could have not blamed me for "letting" it happen in the first place. They also could have actually done something more to punish the people who had bullied me.
- The school could have actually addressed the issue instead of telling me that I was interpreting the situation wrong. They pretty much ignored any complaints and did nothing about them. They should have done an investigation, and kept an open mind instead of automatically protecting their co-worker.
- They said they were going to let the girl's mom know what she was doing, but they never did.
- Made it stop before I cut myself
- I don't know what the school would do. I had trouble with my speech teacher and being confined to the resource room all day. I was very upset and after 8th grade, my mom homeschooled me. As a result, I didn't even get an IEP Diploma. Now I take special art courses but I was told by VESID I probably couldn't pass the GED and I couldn't get assistance to take GED through BOCES.
- Not really bullied just didn't really have friends, school could have helped with that
- The school has a cultural issue and bullying needs to be addressed across the board, not just for students with disabilities.
- Disability awareness presentations or they could have placed me with a different teacher.
- I think I may have been better off if I had been put in the TST BOCES program sooner.
- Disability rights classes for ALL faculty, staff, administration, and students; Direct incorporation of disability issues in pre-existing anti-bullying initiatives, anti-discrimination initiatives

Attachment V

Q27: If you answered no to the last question (are you okay with how the situation was dealt with related to being abused at home), what do you feel should have been done differently:

- There needs to be easy access to attorneys and advocates because PTSD that results from ongoing mistreatment does not put anyone in the right place mentally to confront anything like this even for people w/o a disability. Why should people with disabilities be expected to handle double the emotional distress of the situations in progress?
- I WILL CONTINUE TO SPEAK OUT
- Reported to school
- My mom always makes me come in the kitchen with her when I fight with my brothers. They get to go to their rooms. She says I start it by hitting them in the back. They should get punished because they hit me.
- Sometime times my brothers and I fight and my mom or dad break us up.
- Had an assistant who was too bossy gone now
- In the past, a teacher would provide ABA services incorrectly and punitively when I was 4. I would scream and bang my head every time she came, one of her ideas was to use hot mustard to teach me the difference is yes and no so when I said yes I would get hot mustard. My mother said that was not okay. I am unable to explain what happened in the bedroom with the closed door but I screamed all the time and my mother thought I needed ABA and that even though it was aversive for a year, it must be good for me. Later she learned that if I was tantrumming more than 2 weeks, the teacher was not doing it correctly. I actually regressed because my tantrums were rewarded with escape and I didn't have to work because I was screaming and crying throughout most of the sessions.
- They didn't see it as abuse they just felt that I was being too sensitive and they were just "jokes." I am ok with how it happened because I don't live with them anymore, and I am a stronger person because of it.

Attachment VI

Q30: If you answered no to the last question (do you think the situation was dealt with fairly and appropriately related to bullying at work), what do you think should have been done instead:

- I've been called psycho retard. I've had my schedule suddenly be changed so that they can fire me as a no call no show. I have been told to violate company policy on purpose so that my refusal is labeled insubordinate to get fired....and many other types of discriminatory deception.
- I think they should have done the work and show me how it was done before I did it.
- I think employers and employees should be educated
- SINCE I WORKED WITH SO CALL PROFESSIONAL NOTHING WAS DONE
- Nobody Apologized
- My co-workers did not understand my disability and locked me in a freezer. My manager did nothing to them. One manager was good to me but he was not there all the time.
- The blame was placed on me and not the supervisor. The supervisor should have spoken directly to the one doing the bullying.
- They should have done an investigation. MY boss was docking my hours and when I reported it to his boss, they did nothing. I had the proof my time sheets and my pay stubs, and when I quit he gave me all the hours back that he had taken. I pointed this out it was black and white, and his bosses didn't do anything about it. I felt that they should have had a talk with him about it instead of just kicking me to the curb.