

The Quality Initiative



What People with Disabilities and Their Families Said About Quality of Life

New York State
Commission on Quality of Care
and Advocacy for Persons with
Disabilities

2010

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What people with disabilities said about their quality of life

Opportunity.....Choice.....Freedom.....Acceptance

EXECUTIVE SUMMARY

This report summarizes what individuals said about a wide variety of life areas, including employment, education, transportation, housing, health, community participation and more. The information was collected for the NYS Commission on Quality of Care and Advocacy for Persons with Disabilities' (CQCAPD) Quality Initiative. The Quality Initiative was created to assist the CQCAPD, other state and local government agencies, and community based agencies to move beyond regulatory compliance and ensure that services, supports and standards improve and promote a good quality of life for people with disabilities.

In 2009, CQCAPD in partnership with eighteen organizations involved in providing services and supports by, with, and for people with disabilities, formed the Quality Coalition. Coalition members worked together to learn more about the diverse lives of people with disabilities. With CQCAPD in the lead, the group conducted focus groups with individuals with disabilities and their family members to discuss what constitutes a good quality of life, the challenges that are faced in attempting to achieve a good quality of life, and what still needs to change. People with disabilities and their families were also invited to describe their quality of life in more detail by sending their individual life stories to CQCAPD. Nearly four hundred and fifty people across New York State participated in focus groups and/or sent in stories about their quality of life.

Overall, participants said that they wanted to have the opportunity and freedom to make choices in all areas of their lives. The people participating in focus groups and those who submitted stories also said that they wanted to be accepted and included in their communities, schools and places of work and to be seen as an individual and not be defined by their disability.

The information in this report provides a framework for policy makers, government agencies, advocacy organizations, providers, individuals and family members to use when planning, providing, funding or regulating services for people with disabilities.



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The Quality Initiative



Introduction

In 2009, the New York State Commission on Quality of Care and Advocacy for Persons with Disabilities (CQCAPD), in partnership with eighteen organizations involved in providing services and supports by, with, and for people with disabilities, formed the Quality Coalition (a complete list of Coalition members is attached at the end of the report).

The Quality Initiative was created to assist the CQCAPD, other state and local government agencies, and community based agencies to move beyond regulatory compliance and ensure that services, supports and standards improve and promote a good quality of life for people with disabilities.

Coalition members began working together to learn more about the diverse lives of people with disabilities. With CQCAPD in the lead, the group held focus groups with individuals with disabilities and their family members to better understand what people thought constitutes a good quality of life; what challenges were faced in attempting to achieve a good quality of life; and what still needed to change.

Over four hundred people from around the state communicated with us about their perspectives and experiences related to a wide variety of life areas including employment, education, transportation, housing, health, community participation and more through participation in focus groups and/or sharing their individual stories.

“What do I want?
The same things
you want. I want to
have friends, I want
to belong and I
want to have
enough money to
live on my own.

I don't want to be
afraid of people
and I don't want to
be teased or
ridiculed.

I don't want to be
stopped from doing
things because I
have disabilities.

Just because I have
disabilities doesn't
mean I only want to
be with other
people who have
disabilities.”

Matthew, age 23



“Get involved and work with policy makers. Make sure your needs are known.”

Methodology

In 2008 and 2009, the CQCAPD, with assistance from the Quality Coalition, conducted focus groups and also invited people with disabilities and their family members to describe their quality of life in more detail by sharing their individual life stories.

Focus Groups: CQCAPD conducted 30 focus groups across New York State, with 405 individuals participating. The focus groups varied in size from 8 to 25 people (a complete list of the focus groups is attached at the end of the report).

Participants were asked to answer a series of questions about their quality of life. Some questions were open-ended such as “what does a good quality life mean to you?” Others asked specifically about different areas of life such as housing, employment, education, transportation.

Quality Stories: CQCAPD and the Quality Coalition also wanted to hear from people who were not able to participate in focus groups or who wanted to provide more information about what types of things enhanced their quality of life or what challenges were faced to have a good quality of life.

The information on how to share stories was provided at focus groups, and coalition members distributed the information as widely as possible. Additionally, this request was posted on CQCAPD’s and coalition members’ websites. In total, 43 individual stories were submitted. Excerpts from these stories can be found on the CQCAPD website www.cgcapd.state.ny.us.

Demographic Information

Demographic information forms were distributed at each focus group. Nearly two-thirds (64%) or 259 of the participants responded to the forms, but some did not complete all the questions. The information follows:

Gender: Male = 139 (55%) and Female = 114 (45%) (n = 253)

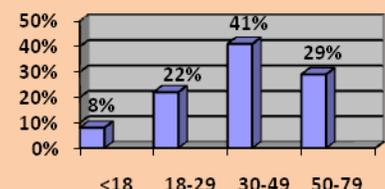
Type of Disability: More than one quarter of the people (27%) identified themselves as having more than one disability and one-half of the individuals identified at least one of their disabilities as a psychiatric disability.¹ A breakout of how individuals self-identified is below.

- Psychiatric 128 (51%)
- Physical 94 (37%)
- Developmental 69 (27%)
- Sensory 39 (16%)
- Other 26 (10%)

Note: groupings are not mutually exclusive (n = 251)

71% of individuals were under the age of 50, and 29% were between 50 and 79 years of age.

Age of Individuals in Quality Initiative Focus Groups
n=254



¹ The focus groups were piloted at the Office of Mental Health’s Recipient Affairs Committee meeting where over 100 people participated.

Ethnicity: A comparison of the New York State census data with the individuals who participated in the focus groups showed that the groups generally reflected the ethnic make-up of New York State. However, there were some differences as noted in the chart below.

Race/Ethnicity	Focus Group Demographics (%)	NYS Census Data (%)
White/Non-Hispanic	65%	60%
Black/African American	16%	17%
Hispanic/Latino	9%	16%
American Indian/Alaskan Native	7%	0.1%
Asian/Pacific Islander	3%	7%

Employment: Over half (52%) of the people in the focus groups were not employed, only 23% were employed full time, and 18% were employed part time. Another 7% did volunteer work. (n = 159)

- Not employed 83 (52%)
- Full time 37 (23%)
- Part time 29 (18%)
- Volunteer 10 (7%)



Income: Individuals who participated in the groups reported their income based on the ranges provided below. Forty-four percent reported an income of under \$20,000. One-quarter reported an income of \$20,000 to over \$80,000. Some people identified themselves as SSI recipients and some of those people either checked “not applicable” or the category “under \$20,000.” (n = 151)

- Under \$20,000 66 (44%)
- \$20,000 - \$39, 999 23 (15%)
- \$40,000 - \$59,999 10 (6%)
- \$60,000 - \$79,000 3 (2%)
- Over \$80,000 3 (2%)
- Not applicable 46 (31%)

Education: Almost half of the individuals in focus groups had graduated from high school and 26% had graduated from college or obtained an advance degree. Slightly over one-quarter (28%) of the participants had not graduated from high school, however, half of those people were under 18 and likely still in school. (n = 157)

- Not graduated high school 44 (28%)
- High school graduate 34 (22%)
- Some college 32 (21%)
- College graduate 27 (17%)
- Master’s degree 13 (8%)
- Vocational or trade school 5 (3%)
- Ph.D, J.D., or some post-graduate work 2 (1%)

Life Areas



“Just because we have a disability doesn’t mean that we are different from you. We want the same things as you do.”

Gregg, age 41

Life Areas

- Housing
- Employment
- Transportation
- Health
- Education
- Personal Relationships
- Community Participation
- Financial Security
- Hopes and Aspirations
- Spirituality
- Leisure and Recreation
- Assistive Technology and Accessibility
- Service Related Issues
- Political Participation
- Government Oversight

Focus Group Findings

CQCAPD staff used the areas of life that the National Council on Disability (NCD) used in their April 2008 report entitled *Keeping Track: National Disability Status and Program Performance Indicators*² to analyze all the information gathered at the focus groups. The areas of life included: housing, employment, transportation, health, education, personal relationships, community participation, and financial security.

Many things people said did not fall into these areas of life and were broken out into the following additional categories: hopes and aspirations, spirituality, leisure and recreation, assistive technology and accessibility, service related issues, political participation and government oversight.

The following is a synopsis of what participants said about each of the areas of life. Each section starts with a quote related to that area from someone in a focus group and/or from an individual story.

² NCD is an independent federal agency established to advise the federal government on disability related issues.

Housing

“Housing Equals Home”

The people who participated in the focus groups and submitted individual stories lived in all different types of housing including, but not limited to, their own home/apartment, with family members, specialized housing (e.g., special housing for people with visual impairments), supportive housing, community residences, individualized residential alternatives (IRAs), adult homes and homeless shelters.

The over-arching themes related to housing were:

1. Good quality housing

Indicators of good quality housing were the ability to have clean, safe, and well-maintained homes located in safe neighborhoods. Some individuals said that they lived in housing that lacked sufficient heat, hot water and air conditioning which detracted from their quality of life. People also stated that they would like to have some privacy, including having their own bedroom and bathroom, and to be able to use the kitchen and all areas of group home settings. Participants wanted respect for culture, likes and values, as well as style and taste in their homes.

People with sensory disabilities identified numerous things that are lacking and affect the quality of their housing. These items include, Braille addresses on apartment buildings, flashing lights for doorbells and smoke alarms, and sign language interpreters to assist in obtaining housing, including Section 8.

2. Choice and availability in housing

Individuals stated that stable, permanent housing is hard to find and that more financial support through SSI, rent subsidies and utilities would be helpful. Additionally, they would like to have smaller households, to have the ability to personalize space and have visitors, to be able to have a pet, and to not be required to go to programs as part of their housing. People also wanted to live in places that are more integrated into the community. Participants with physical disabilities said that there is a lack of affordable, accessible housing for people with families and they often had to choose to live by themselves instead of with their family. Many of the people who sent in their stories discussed how positive their life was because they were currently living in a place that they chose.

3. To be able to live as independently as possible

Having the supports needed to live as independently as possible were important for good quality of life. Skilled staff who are paid well, respectful, courteous and who know the individuals in the home well were important to people living in group homes or other supported housing settings. Some individuals stated they would like to see lower staff turnover and more affordable home care. Some family members said that having good communication with their children’s housing staff was important for good quality of life. Some people also said that feeling empowered in their home was important; for example, being able to have a say in house rules that affect them.



Employment

"Give us alternative career opportunities to food, filth, filing, folding and flowers. Ask a person what job they want and plan a goal to get there."

All of the adults participating in focus groups and submitting stories said that employment was very important to their overall quality of life. The three major things that people wanted related to employment were:

1. Meaningful work

Meaningful work was defined as something that a person wants to do or has the education and experience to undertake. Other issues that were identified as important were salaries that pay enough to allow one to support oneself and a family, benefits and paid time off.

2. Choice of jobs and hours of work

Individuals reported that they often were not given a choice of jobs to pursue or hours to work. Participants with psychiatric and developmental disabilities said they wanted more choice of jobs outside of the disability field and did not like working in sheltered workshops.

3. Support to get the job you want

People appreciated and wanted more of the programs that are available to assist in obtaining and keeping employment, such as job coaches, free tuition at some colleges for individuals receiving public assistance, Social Security's programs for employment support, Independent Living Centers, and vocational employment support for individuals with disabilities services. The American with Disabilities Act was recognized as protecting their rights to obtain and retain employment.

Factors that would improve quality of life included the ability to work without losing benefits, increased accessibility, awareness of disabilities and sensitivity from others. While some people found employers who were willing to hire people with disabilities and make accommodations, many reported that it was difficult to find employers with a willingness to make accommodations.

VESID was identified by participants with psychiatric and sensory disabilities as a program that could help them find work but had many limitations. They felt that there is a long wait to access services, the VESID system is difficult to work with when flexibility is needed, and the types of jobs available are limited.

"Finding jobs and job developers and coaches who are used to working with college-educated people is difficult."

Rita, age 46

"Although I have many challenges I still want to have a job."

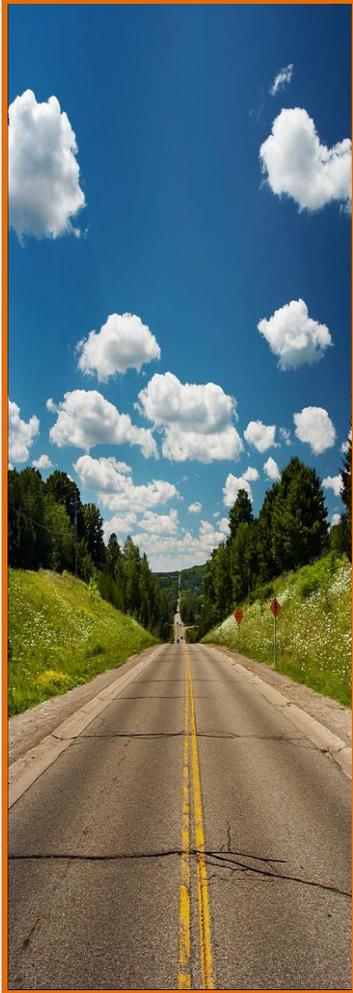
Lisa, age 19



People said they would like more information about jobs, training opportunities, and the impact working has on benefits.

Transportation

"To be included, you must have transportation."



Even though there are differences throughout the state in local transportation systems, there were three common themes related to transportation.

1. Affordability and availability

A common thread with transportation was the word "affordable." People appreciated the programs that provided reduced fare or free public transportation such as the Half-Fare program. Individuals also wanted an opportunity to learn to drive and be able to afford to purchase and maintain their own vehicle.

Having transportation that is available near their homes, on weekends, off-hours and in rural and suburban areas was identified as important and makes an impact on participants' ability to obtain and keep employment and to participate in cultural, recreational and spiritual activities.

2. Accessibility

Accessible fixed route mass transportation was also important. People said that there is a need for more buses with lifts, elevators in subway terminals that are in working order, and accessible train and subway platforms. Some individuals stated that they are charged more to use public transportation because they use a wheelchair and that buses do not accommodate some power wheelchairs.

Participants reported that airlines and rail transportation services expect them to travel with a companion and as a result they can be denied passage if travelling alone. Individuals who are blind noted the need for support service providers in airports.

Getting approval for an accessible van was very difficult. Additionally, accessible full service gas stations were identified as important and often difficult to find.

3. Paratransit issues

Paratransit is accessible curb-to-curb, demand-response transportation services provided to people who are elderly or have disabilities, are without personal means of transportation or do not have the functional ability to ride fixed-route transportation. Although participants appreciated paratransit services, multiple problems were identified. These problems included limited hours and catchment areas and unreliability or unavailability of service. Many people noted that paratransit required advance reservations, making it impossible to use these services for more spontaneous travel. Some individuals reported rude or disrespectful drivers on paratransit services. Additionally, some individuals with sensory disabilities stated that they have experienced having the paratransit service vehicle leave without them because they could not hear and/or see its arrival.

Health

“Doctors are afraid of people with disabilities and don't talk directly to people with disabilities.”

The three over-arching themes related to health were:

1. Overall health status

People identified good physical and mental health as important to their quality of life. Most participants were not happy with their overall health status and felt that they lacked information about health care, health insurance, medications and ways to promote good health and nutrition. Focus groups comprised of individuals with psychiatric disabilities most often identified health as the one area of life they wanted to change. They wanted to be healthier physically and mentally.



2. Access to insurance and health care

People valued access to quality medical and nursing providers, therapists and other health related services and programs. Other health related services included advocacy organizations, self-help and peer networks. Parity for mental health coverage was also valued.

While participants in focus groups appreciated their health insurance, whether it was private or public, individuals identified many deficiencies in existing insurance coverage. Some insurance plans do not support choice, respond to individual needs, offer alternative treatment options, and do not provide coverage of needed services, such as assistive technology and medication. Many people stated that not all disabilities or conditions, such as autism, are covered under insurance. There are several different ways to lose insurance coverage (lose job, age out, get job, get sick, etc.) and participants did not like having to choose between Medicaid, or working and losing health insurance. Additionally, individuals reported difficulties obtaining medical care because many providers do not accept Medicaid.

People with physical and sensory disabilities said it can be hard to find physically accessible health care, such as accessible beds in emergency rooms, testing sites and doctors' offices or sign language interpreters in doctors' offices and hospitals.

The availability of treatment varied depending on where a person lived. New York City and the Capital District were two of the places identified as having more health resources than other places. However, participants from all over the state said there was a lack of access to alternative health care and to specialists, such as child psychiatrists.

3. Attitudes of medical providers

There was a need for increased sensitivity and disability awareness by medical providers and first responders. Individuals wanted medical providers to speak directly to them and respect them and their need for privacy. Participants thought medical providers should be more tolerant of different behaviors and provide people with more input into their treatment options. Individuals with psychiatric disabilities wanted more choice and input into their care and had many concerns about forced care, like medications and hospitalizations.

Education

“Individualized Education Programs (IEPs) that mean something and are not just a golden sticker.”

People participating in focus groups and submitting individual stories had experience across the education continuum: almost half of the individuals in focus groups had graduated from high school and 26 percent had graduated from college or obtained an advanced degree and a large number were still in school.

Several of the participants who sent in their individual stories said achieving their educational goals was very important to their quality of life because it was an important factor in getting a job of their choice.

“School finally listened to me when I told them I want to learn to read and I’m working with a reading teacher to try to learn to read so I can get places if my mom can’t drive me.”

Rosemarie, age 20

The top 3 issues related to education were:

1. The ability to get assistance, support and/or funding

People wanted help to obtain a college education and believed that colleges should have a place for everyone regardless of their disability. It was stated that there is not enough information about education and training opportunities, and that more knowledge about accommodations in education, entitlements and self help was also important. Role models and mentors were identified as supports that would be helpful.

While some individuals identified Vocational & Educational Services for Individuals with Disabilities (VESID) as helpful, others had concerns about limitations within VESID. They believed that VESID should do more to assist and support people who want to go to college and some experienced a long wait for VESID services.

2. The ability to get a quality education based on individuals’ abilities, not their deficits

Participants wanted meaningful individualized plans for education and more assistance to enhance their likelihood for success. People also identified a need to have interesting and age appropriate education programs; learn practical skills; be prepared for post secondary education; and have more experienced special education teachers, with lower turnover rates. Many individuals identified a need for awareness training on disabilities for educators.

Of particular concern to many participants are the limitations of the IEP diploma. Several people stated that the IEP diploma is not useful because it is not recognized as a high school degree and, thus, limits job possibilities and acceptance to college. Additionally, participants reported they are not informed of the limitations of the IEP diploma while they are in school and they do not believe they have a choice in what type of diploma they can pursue.

3. The ability to pursue one’s own dreams and goals in education

Young people with disabilities wanted an opportunity to get a Regents Diploma and go to college. Some individuals said that they would like vocational program staff to be more supportive of individual goals and not say they are unrealistic. Participants also wanted to have lifelong learning opportunities.

Personal Relationships



“Close relationships are the best support system an individual with disabilities can have.”

Leonard, age 54

“Social connectedness with people who aren’t being paid - beyond mom, dad and school.”

The three major themes related to personal relationships were:

1. Choice in personal relationships

People stated that they would like to be able to have relationships and a choice in partners and be respected for their individual choice. Individuals who lived in group settings stated they would like to have a place in their residence where they can socialize with friends without provider interference.

2. Acceptance, inclusion and respect of others

Participants said they wanted acceptance from others and to be known as a human being and not be defined by their disability. People said they wanted to have a sense of belonging, to feel less isolated and to be a support for one another. Individuals and their family members wanted to have integrated social opportunities with community members and to have friendly neighbors.

3. Support of family/friends/peers

People said having a support system, such as a circle of friends, and helping peers with recovery, were important to a good quality of life. Quality indicators in the area of personal relationships were identified as having opportunities to learn from outside the human services system through peer support, being able to raise children without others telling them what to do, and being able to do things that family and friends without disabilities do. Participants wanted to be able to educate family members about disabilities, especially mental illness.

“I would like to settle down with my girlfriend someday and start a family of my own.”

Jason, age 31

Community Participation

“Having services available in the community and being able to take walks and shop on your own.”

The three themes related to community participation were:

1. Inclusion, integration and acceptance

People wanted to be accepted in their communities and be treated like a “normal person” instead of being stared at or laughed at. Many called for increased public awareness campaigns to decrease stigma and others said that the ability to participate and be seen participating in civic, cultural, spiritual and recreational activities is important to quality of life and can help reduce stigma.

2. Accessibility

Individuals with physical and sensory disabilities identified many accessibility issues that prevented full community participation. Having access to stores, libraries, banks, restaurants, parks, theaters, etc., and clear, unobstructed sidewalks and accessible parking was important to quality of life and often lacking in communities where people lived. The availability of sign language interpreters in community venues was noted as lacking for people who are Deaf or Deaf-blind and prevented them from community participation.

3. Assistance and support

Participants wanted more help finding support groups and other community groups and events in which they could participate. Individuals living in group homes said that there was not enough staff in group homes to assist people who wanted to participate in community events and when they were able to participate, would like more choice in selection of activities.

“I have always supported or been a part of my community organizations and the many community residents who are a part of them.”

Arthur, age 79

“Have you ever imagined what life would be like without friends or neighbors to make you feel welcome? I live that life every day.”

Rosemarie, age 20



Financial Security

“Having enough money to pay the bills and a bit left over.”

The over-arching themes relating to financial security were:

1. People want to be self-sufficient

Being self-sufficient and having the ability to handle their own money were identified by participants as indicators of quality and as one of the things they would like to change about their current situation.

2. SSI, Medicaid & Medicare are important

Individuals valued SSI, Medicaid and Medicare and their service providers’ assistance. Many people also expressed concern about the impact budget cuts to these services would have on their already fragile financial situations.

3. Accessing benefits is complicated and difficult

The process for obtaining benefits like SSI, Medicaid and Medicare was characterized as complicated and difficult. Participants experienced long delays in obtaining benefits – one person said it took two and a half years to obtain Social Security. People had a difficult time getting materials about benefit programs in accessible formats, as one person with a vision impairment said, “If you don’t have someone to read it for you, you are up a creek.” Individuals said obtaining benefits often requires making numerous appointments, and if you get sick or your transportation fails, that causes delays in the process.

“The worst obstacle to a better life is dependence on Medicaid for treatment and medication which prevent taking any job that would cause loss of Medicaid. One feels imprisoned by the system which prevents progress and kills the spirit.”

Anonymous, age 35

“I pay for my own heat, electric and telephone out of my disability check. I do my own shopping in a neighborhood where transportation and stores are close-by. The greatest help is rental assistance. Without that benefit I would be in a shelter.”

Fred, age 48

Hopes and Aspirations



“My parents always asked the question, ‘How do we know what Mathew can really do unless we let him try.’”

Mathew, age 23

“To have passion, purpose and meaning in life.”

People who participated in focus groups and submitted their individual stories said that having hopes and aspirations is very important to their quality of life. They identified the following as being supportive of a person’s hopes and aspirations:

1. Support to reach goals

Some participants stated that they would like to have more support to reach their goals and dreams and be able to make a contribution to the best of their ability.

2. Autonomy

People wanted autonomy; to have their life under their control and to be responsible for their actions.

3. Eliminate environments that create learned helplessness

Individuals said they wanted to be able to take care of themselves without relying on others all the time. Participants wanted to self-advocate and speak up for themselves more often.

“The most important thing to me is to love, share my dreams, my faults, to be able to make mistakes, and to be able to learn from them.”

Joe, age 39

Spirituality

"I have connected to other people in the community by being a self-advocate and being involved in my church."

I am a person with cerebral palsy... My church actually asked me what I needed to get around in the church."

Ray, age 30

The things most important to people related to spirituality were:

1. Acceptance and support

Faith-based communities varied in the level of acceptance and support participants with disabilities said they experienced. Some spoke of efforts that their places of worship made on their behalf: one individual said that her church provided an aide for her child during the service; another was in a church program designed for individuals with developmental disabilities; and yet another person said that their synagogue provided disability awareness training for rabbis. Other individuals talked about places of worship that provided sign language interpreters or large screens for people with visual disabilities. Participants stated they would like their faith-based organization to be more understanding of people with disabilities and recommended education on disabilities for faith-based communities.

2. Choice

Individuals said they wanted choice in where to worship and that choice was limited when places of worship were not accessible or welcoming to people with disabilities.

3. Accessibility

Churches, synagogues and other places of worship are exempt from the Americans with Disabilities Act and many places of worship are not accessible to persons with disabilities. As noted above, some places of worship have made accommodations and participants said they thought more education regarding the needs of people with disabilities would be beneficial and help improve their quality of life.

Leisure and Recreation



"I play power wheelchair soccer. I really love it. It gives me the opportunity to be part of a team, something that I had not had a lot of experience with in the past."

Samantha, age 22

"Kids my age are playing hockey and football in the street while I sit on my front porch watching because they won't play with me."

The three issues relating to quality of life in the area of leisure and recreation were:

1. Affordable or free activities nearby

Overall, people said having a choice of accessible, affordable leisure and recreational activities that are available in their communities was important to their quality of life. Many identified specific programs in their communities and others said they would like more information about affordable or free activities that are available in their community. Individuals participating in focus groups also said they were interested in more intellectually stimulating activities than are often offered to people with disabilities. Some participants wanted the ability to choose not to participate in all organized activities that their housing program or service program offered so that they could have some "down time."

2. Accessible activities and recreational facilities

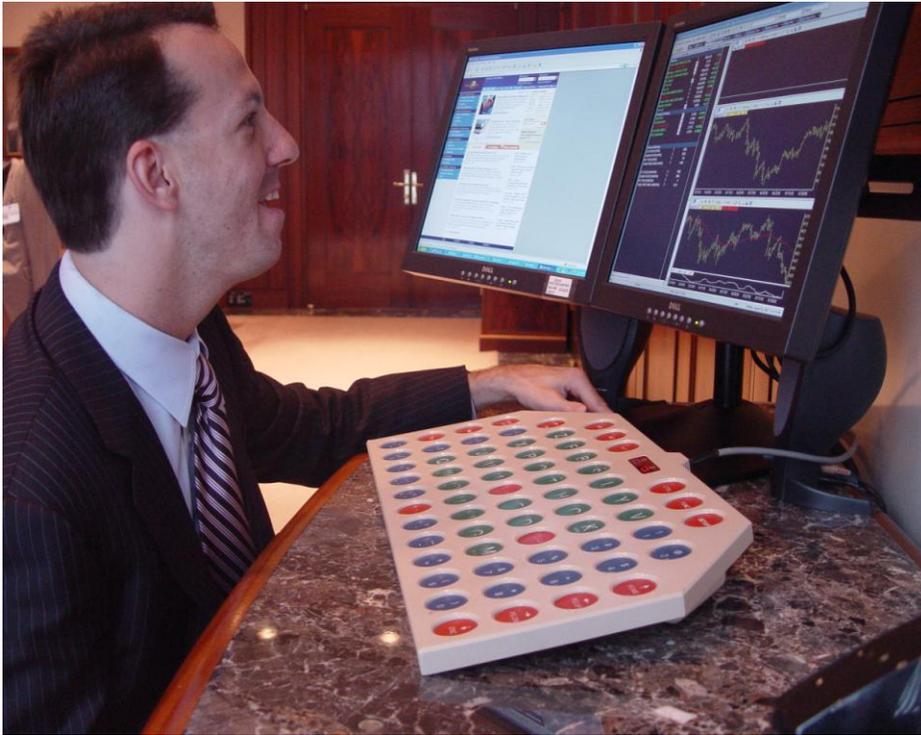
There is a need for more accessible environments for leisure and recreation, such as playgrounds, parks, dressing rooms and gyms, and captioning on boards at sporting events and movies. Some people suggested allowing support staff to participate at reduced cost or free which would assist in having more individuals with disabilities participate in leisure and recreation activities.

3. Activities for children and youth

Programs needed include recreation facilities for children with physical disabilities, affordable and creative activities for youth and extra-curricular sports for youth with disabilities. Some programs do exist; however, there are sometimes long waiting lists, age limits and ability restrictions.

Assistive Technology

"Full access means not having to worry about accessibility."



The top issues related to supporting quality of life in the area of assistive technology and accessibility were:

1. Full accessibility

Never having to worry about accessibility means the elimination of heavy doors, small restroom stalls, availability of interpreters anywhere you go, and buildings with lights and sound for alarms. People also expressed concern that emergency shelters were not fully accessible and that emergency preparedness plans had not taken the needs of individuals with disabilities into account.

2. Access to assistive technology

Some assistive devices, such as standers, hearing aides, ramps and walkers, are needed but may not be covered by insurance. When they are covered, the process to obtain them is long and complicated. Assistive technology, including captioning and videophones, should be available at home and in public areas, such as work, airports, hospitals, movie theaters and hotels.

"I started talking using a computer touch screen that the school bought for me. I used a stander, wheelchair, braces, walker and a lot of other equipment to finally walk on my own."

Rosemarie, age 20

Service Related Issues



“Even people who are supposed to help are sometimes afraid.”

Lisa, age 19

“Ask us how to provide supports. It would save money down the road.”

The 3 major themes related to the services that people received or would like to receive were:

1. Help navigating the system

Participants would like a clearinghouse to help individuals with disabilities find out about the services and assistance that are available statewide and in their area. They valued those services that helped “hook you up” with the things that people needed, including legal assistance and accessing entitlements. Peer support and advocacy was identified as often helpful in this regard.

2. Support independence

Individuals want services to support their independence and not continued dependence on service systems. They want service providers that provide challenges, encourage growth and understand that failure is part of the process. Service providers should help individuals plan for their future and “let people go” when they decide it is time to move on.

3. Self-Direction/Choice

Participants want to have more self-direction and choice in services, staff and activities. One participant said that people with disabilities’ lives depend on “professional assessments” to get housing and services and that an individual’s preferences and desires were often not taken into account.

Government Oversight & Political Participation

"The ADA must be more strictly enforced with landlords, health agencies, city agencies, transportation providers and hospitals."

"I would like to be able to choose who to vote for in elections and not have staff tell me who to vote for."

The issues pertaining to government oversight were:

1. Americans with Disabilities Act (ADA) and Individuals with Disabilities Education Act (IDEA)

People stressed that the ADA and IDEA are important and helpful laws because they provide timelines and mandates for serving people with disabilities.

2. Inconsistent enforcement

Participants stated that their experiences differed and that the ADA is not fully enforced in all areas and oversight of services and protection of rights is not consistent across state agencies.

3. Increased awareness of ADA

Individuals said that they believed there is a general lack of awareness about the ADA which hinders enforcement.

The issues related to political participation were:

1. Voting and participating in government are important

People valued being a registered voter and said that participating in government, like attending city council meetings, was important to them. Participants with developmental disabilities said they want to choose who to vote for without staff telling them. Many people thought a good quality indicator for a service provider would be the number of people who are helped to become registered voters.

2. Accessible polling places

Not all polling places are accessible and people want more information about how to use voting machines.



Next Steps

The information in this report provides a framework for policymakers, government agencies, advocacy organizations, service providers, individuals with disabilities and family members to use when planning, providing, funding or regulating services for persons with disabilities. CQCAPD and its Coalition members will share the report with state and local government officials and other community partners to encourage inclusion of this expanded concept of quality in all aspects of planning and service delivery.

Quality Coalition Members

- Association for Community Living (ACL)
- Families Together in NYS (FTNYS)
- Mental Health Association of NYS (MHA)
- Mental Health Empowerment Project (MHEP)
- National Alliance on Mental Illness of NYS (NAMI)
- NY Association of Psychiatric Rehabilitation Services (NYAPRS)
- NYS Association of Community and Residential Agencies (NYCRA)
- NYS Council for Community Behavioral Healthcare
- NYS Developmental Disabilities Planning Council (DDPC)
- NYS Independent Living Council (NYSILC)
- NYS Rehabilitation Association (NYSRA)
- NY Vision Rehabilitation Association (NYVRA)
- Parent to Parent of NYS
- The Regional Center for Independent Living (RCIL)
- Self Advocacy Association of NYS (SANYS)
- NYS Office of Mental Health (OMH)
- NYS Office of Mental Retardation and Developmental Disabilities (OMRDD)
- NYS Commission on Quality of Care and Advocacy for Persons with Disabilities (CQCAPD)

Focus Group Sponsors

Coalition for the Homeless- NYC

Coalition for the Institutionalized, Aged and Disabled- NYC

Developmental Disabilities Planning Council Consumer Caucus- Statewide

Families Together- Youth Power- Statewide (2 groups)

Families Together- Statewide

Harlem Independent Living Center- New York City

Independence Foundation Youth group- Buffalo

Independence Foundation- Family group- Buffalo

Mental Health Empowerment Project- Statewide (2 groups)

Mental Health Empowerment Project- Syracuse

Mental Health Empowerment Project- Albany

National Alliance on Mental Illness- Queens

National Technical Institute for the Deaf- Rochester

NYS Independent Living Council- Statewide

NY Vision Rehabilitation Association- New York City

OMH Recipient Affairs Committee- Statewide (4 groups)

Parent to Parent- Schenectady

Parent to Parent-Massena/Canton

Parent to Parent- New York City

Regional Center for Independent Living- Rochester

Self Advocacy Association of NYS-Regional (2 groups)

Self Advocacy Association of NYS- Statewide (3 groups)

Westside Federation for Senior and Supportive Housing - New York City