



CQL and NY State: Certified Trainers/Interviewers Webinar

3rd Quarter 2018
September 24, 2018

**Denise Walsh, Beckie Austin
& Anne Buechner**



**The Council on
Quality and Leadership**

www.c-q-l.org



Today's Agenda

- New York State Updates, Denise Walsh and Beckie Austin
- Personal Decision Making: Civil & Human Rights, Anne Buechner
- Questions/Answers
- Plans for 4th Quarter 2018



New York State Updates

Denise Walsh & Beckie Austin

- New York State Managed Care Plan
 - Draft Plan Updates
 - Roll Out Information
 - Timelines
 - I Am Assessment
 - Life Plan
 - Other



Supporting Decision Making

Anne Buechner



What is the difference?

- First, think about your rights and those you exercise
- Next, think about the rights of people with disabilities who you support
- How do people with disabilities experience rights?
 - Same?
 - Equal?
 - Should it be?



Basic Human Rights

“All human beings have these basic rights:

The right to choose where you wish to live

The right to choose which people you wish to be with

The right to make up your own mind about what you want to do

The right to say “NO” when you don’t want to do something”

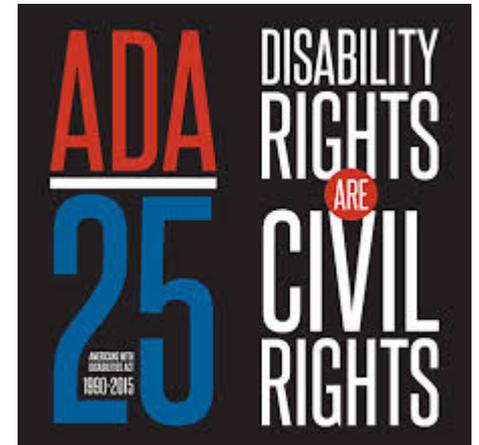
A Manual on Self-Advocacy by Paul Williams & Bonnie Shoultz

Education, Experience and Exposure

The logo for 'The 3Es' features the word 'THE' in a blue sans-serif font, positioned above a light blue rectangular background. To the right, the number '3' is rendered in a large, bold, orange font, followed by the letters 'E' and 'S' in a large, bold, blue font.

Basic Human Rights

- The right to decide what I eat, including to have a say in how my food stamps are used.
- The right to access my money. Do people pay for their own birthday or holiday gifts? Do people “earn” their won money for good behavior?
- Due process and Human Rights committee



Things Can Change: Civil Rights

“Never doubt that a small group thoughtful, committed people can change the world.

Indeed, it’s the only thing that ever does.”

Margaret Mead

Access to the Courts

- Can a person with a disability take someone to court if they do not have the support of an advocate or another unbiased person who is willing to support them?
- What are some ways that people with disabilities have been able to use the court system?
- What are some ways the court system needs to improve to become more accessible?

Right to Free Association

- What are the barriers to free association that are imposed upon people with disabilities?
- Rules about...
 - Visitors
 - Social media
 - Phone use
 - Visiting with co-workers
- Transportation?
- Work Shops?



The Right to Contract for, Own or Dispose of Property

- Can a person own a home when they make sub-minimum wage?
- What about subsidized housing?
- What about financial limits and the way they affect benefits?



Equal Protection and Due Process

- Can people really fight guardianship?
- Do people have a choice in whether they have a representative payee for their SSI or SSDI?
- Do they know that they have that choice?
 - CQL sponsored webinars on Supported Decision Making
 - The Quality Trust, Washington, DC.



Freedom from Cruel or Unusual Punishment

- Is a life sentence in a state institution or other restrictive environment cruel and unusual?
- What about chemical restraints?
- What about unreported/underreported abuse and neglect?

The logo for CQL (The Council on Quality and Leadership) features the letters 'CQL' in a bold, blue, serif font. A gold swoosh is positioned above the 'C' and 'Q'.

CQLSM Freedom of Speech & Free Expression

- Can you really have freedom of speech when your entire life is controlled by an agency?
- Can you tell the truth and be believed?



Right to Marry, Procreate and Have Children

- Can a person with a disability do this without a guardian's consent?
- What happens when sex is against the rules of a group home?
- What happens when it is against the rules of a family home?
- What about informed consent for birth control?



The Right to Vote

- Does guardianship extend to voting rights in your state?
- Are there attitudinal barriers with poll workers? Parents? Staff?
- Are their physical barriers to voting?
- Transportation
- Polling place barriers
- Non accessible voting machines



The Right to Privacy

- Your entire history is on paper for any staff person to read... (or now, electronically available)
- Self advocates statements include:
- Hundreds of people have seen me naked and no one has ever asked me if it is ok.
- Or simply put... TOO MANY HANDS TOUCHING ME
- Self advocates who live in group homes state that privacy is a constant fight.
- “Staff open bedroom doors without knocking.”
- “I cannot have private conversation.”



Supporting & Developing Self Advocacy

Tennessee Williams Quote:

“Caged birds accept each other but flight is what they long for.”





Self-Advocacy Beginnings

“You do not take a man who, for years, has been hobbled by chains, liberate him, bring him to the starting line of the race, saying:

You are free to compete with the others.”

Lyndon B. Johnson



Why Support Self-Advocacy?

- People in full life service have very little experience making decisions.
- We, as providers, need to provide the situations in which people can make choices.
- We are charged with preparing people to make the decisions they will be asked to make with HCBS.

What Is Self Advocacy?

What It is NOT:

People sitting around and complaining

A program

Only for people who can talk

Keeping everything the same

Keeping to yourself

Putting yourself down

Playing it safe, doing the same stuff

Sleeping through your dreams

Other people making decisions for you

Not taking any chances

Staying home

Staying angry

Being questioned



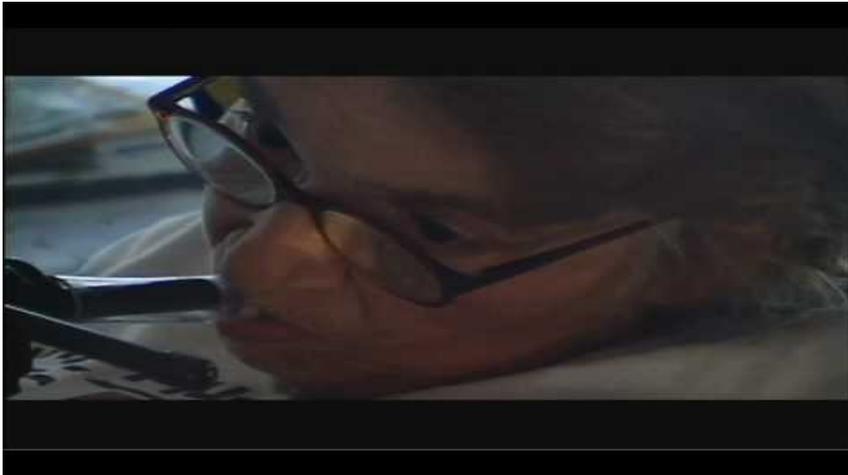


How to Support Self Advocacy Movements?

Personal Self Advocacy

- Assisting and orienting people to ask for what they want
- Supporting people to know it is ok to say NO!
- Looking for opportunities to say YES.
- Teaching people how to have dreams for their lives.

<https://www.youtube.com/watch?v=KKNgq79QnSI>



Body and Soul

Diana and Kathy

Diana and Kathy met in a nursing home in Freeport Illinois. Because of self advocacy they were able to move out of the nursing home and support each other body and soul. Their friendship and life of mutual support spanned a lifetime.



Teaching Self Advocacy

- Think of one person you work with.
- How can you support her/him to learn how to advocate (speak up) for her/himself?
 - Asking new staff for help
 - Asking for support with something person wants from the store



How Do We Support Self Advocacy?

- Agency based self advocacy
- Start an advocacy group
- Hold elections
- Talk to the self advocacy group about what they want to see changed at the organization
- Involve the self advocates in interviewing ALL potential staff
- Involve the self advocates in staff evaluations
- Include self advocates in all agency committees
- Provide self advocacy training



How Do We Support Self Advocacy?

- Statewide and National
 - Teach self advocates about the issues related to them.
 - Call! Call! Call! Four phone calls to a legislator and the issue is considered important.
 - Support the self advocates to visit their legislators. Put a face on the issue, it is hard to say know when your constituent is in front of you!
 - Join SABE, Join ASAN, Join The ARC, Join TASH
 - Support people to attend conferences to learn about the issues.



Example National Self Advocacy

- Elizabeth Weintraub
 - The Association of University Centers on Disabilities (AUCD)
 - Serves as a senior advocacy specialist
 - Addressed medical decision making during Supreme Court nomination proceedings
 - <https://www.c-span.org/video/?c4748100/disability-activist-testifies-brett-kavanaugh>

Written Testimony of Elizabeth (Liz) Weintraub Senior Advocacy ...

<https://www.judiciary.senate.gov/download/weintraub-testimony>



Self Advocacy Resources

- For more information on the rights visit the following websites.
 - WWW.C-Q-L.ORG
 - WWW.SABEUSA.ORG
 - WWW.GOVOTER.ORG
 - <http://www.selfadvocacyinfo.org/>
 - <http://selfadvocacyalliance.org/>
 - <http://www.gmsavt.org/>
 - <http://www.selfadvocacyonline.org/>



Person Focused Resources

Person Centered Thinking Tools

Personal Outcome Measures®

- www.c-q-l.org

Supporting Families / Lifecourse Framework

- www.supportstofamilies.org

CMS HCBS Rules

- <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Supports/Home-and-Community-Based-Services/Home-and-Community-Based-Services.html>

Person Centered Thinking Tools

CQL Person-Centered Plan Template

- www.c-q-l.org/HCBS-ACT
- Click on 'Person-Centered Plan Template' on left-side navigation menu





CQL Seminars In New York

<https://c-q-l.org/news-and-events/upcoming-cql-seminars-in-new-york>

Cutting-Edge Quality Improvement: Appreciative Inquiry and Data Analysis

10/9/18 • New York, NY • \$75/attendee

- Gain deeper insight into the ideals of AI
- Hear examples of how AI can be used by providers
- Learn about the resulting positive culture shift
- Discover the benefits of data in assessing AI approaches
- Find out how data can influence organizational decision-making
- Identify key data points and cross-analysis techniques



Turning Dreams into a Life Plan Using Outcomes

10/11/18 • Rochester, NY • \$75/attendee

- Learn about discovery through the Personal Outcome Measures®
- Explore how it can directly inform the Life Plan
- Uncover challenges that organizations often face
- Hear stories of success in planning
- Receive guidance in improving accessibility for people supported
- Find out how to empower people supported in the process

- Questions & Answers
- Plans for Next Quarter's Call





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