Developmental Disabilities Lecture Series

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Changing Organizations to Deliver Services that Lead to Community Inclusion

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Changing Organizations

The Council on Quality and Leadership (CQL)

• Vision – A world of dignity, opportunity and community inclusion for all people.

• Mission – CQL is dedicated to the definition, measurement and improvement of personal quality of life for people receiving human services and supports.

Changing Organizations

Where are we now?

• Living
• Working
• Leisure
• Culture
• New vision...

Changing Organizations

New Jersey Statewide Transition Plan

• Funding for support follows the person
• The opportunity for people to seek employment in a competitive and integrated setting.
• Engage in community life
• Control of personal resources
• Same access to life as someone who doesn’t use services

Changing Organizations

New Jersey Statewide Transition Plan

Must promote...
• Individual initiative
• Autonomy
• Making independent choices
• Tenancy agreements
• Privacy (lockable doors)

Any modification must be based on assessed need, must be justified and documented in plan

Person Centered Planning

• Driven by the person
• Directed by the person
• Timely
• Needs, preferences, quality of life
• At least annually
Changing Organizations

Home and Community Based Services

- Greater community access
- Receiving services to the same degree as others
- Choice of living situations
- Person Centered Plan based on the person's needs and preferences
- Optimize individual initiative, autonomy, and independence in making life choices
- Protection under tenancy laws
- Private sleeping unit and personal decor
- Providing information in plain language

Home and Community Based Services

- Freedom and support to control their own schedule and activities and have access to food at any time
- Information and support to ensure that the individual directs the process to the maximum extent possible, and is enabled to make choices and decisions.
- Offers choices to the individual regarding the services and supports the individual receives and from whom.
- Records the alternative home and community-based settings that were considered by the individual

All Efforts for Quality are Not Equal

Level of Quality

+100

Quality Enhancement

-100

Quality Assurance

Compliance with Health and Safety Requirements

Personal Outcomes Measures

- People are connected to natural support networks.
- People have intimate relationships.
- People are safe.
- People have the best possible health.
- People exercise rights.
- People are treated fairly.
- People are free from abuse and neglect.
- People experience continuity and security.
- People decide when to share personal information.
Personal Outcomes Measures

**MY WORLD**
- People choose where and with whom they live.
- People choose where they work.
- People use their environments.
- People live in integrated environments.
- People interact with other members of the community.
- People perform different social roles.
- People choose services.

**MY DREAMS**
- People choose personal goals.
- People realize personal goals.
- People participate in the life of the community.
- People have friends.
- People are respected.

**MY FOCUS**
To learn as much as possible about the person’s...
- Priorities
- Preferences
- Perspective
**Personal Outcomes Measures**

**What can you do with what you have learned?**

- POM interview can inform the Person Centered Plan
- The data can also be used in the following ways:
  - To inform the organization's strategic plan
  - To learn about trends
  - To compare one year to the next to see if support modifications made a difference.
  - To look at state/national trends
  - To inform strategies for the Basic Assurances®

**Changing Organizations**

- The person
- Circle of Support
- Person Centered Planning
- Supported Decision Making
- Shared Leadership
- Make sure your actions match your words.

**Changing Organizations**

- Presume Competence
- Right to make unwise decisions
- What decisions can I make myself
- What parts do I need help with
- Who is the best person to help
- Respect
Living

• How many ways...
  • Rentals
  • Home ownership
  • Landlord
  • Housemate matching
  • Home share
  • 24/7 or a few hours a week
  • Creating family environments
  • Respite
  • Keeping families together
  • Accessible Tenancy Agreements

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Working

• Small business ownership
• Social Enterprise
• Retirement planning
• Getting jobs like people get jobs
  • Job sharing
  • Job carving
  • Job creating
• Career planning – resume – business cards
• Finding a passion and loving that you do

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Leisure

• How to have fun...
• Just going for it...
• The right to...
• The right support – knowing when to step back and when to offer help.
• Connection – Relationships – Social Capital – Social Roles

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Social Capital

• Increased health (physical and mental)
• Increased safety
• Reciprocity
• Trust
• Quality of life is enhanced through social ties
• Interdependence

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Social Roles

• Enriches our lives
• Enriches the lives of others
• Valued roles
• Giving back to the community
• Active rather than passive
• Responsibility and action
• Purposeful
• Recognized
• Respected

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Physical integration is not the same as social integration although it can lead to greater social integration.
• Enforced segregation vs. Chosen comradery.

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What is stopping us?
changing organizations

• first you have to show up
• then be known
• then interact
• shared experiences
• contribute

what is stopping us?

• transport
• housing
• employment
• communication supports
• service culture/rules
• buildings
consider if these are economic issues or disability issues
not people with disabilities!!!

what is it that the person wants to do?
• what are the benefits of doing this?
• what are the consequences of not doing it?
• what could go wrong?
• how likely is it that something could go wrong?
• how easy is it to anticipate or prevent something going wrong?
• what would the consequence be if it did go wrong?
• how can we reduce the risk by working with what we know of the likelihood, prevention, anticipation, or consequence of something going wrong?

where to start?

• fixed service models designed prior to the person’s arrival
• people have to fix into the services available diminishes the opportunity for a good fit
• one size does not fit all – design with people
• suit the services needs rather than the person’s
• fixed service models are non-negotiable
• when services are driven by staffing patterns not individual needs – the losers are the people

where to start?

• cease developing services for people
• make all aspects of your service negotiable
• place the power in the hands of the people
• start from scratch – innovate ideas for life
• limit bureaucracy or management practices that impair people developing individual supports
• devote annual resource for remodeling

rate of acceptance varies by knowledge of what is happening

• 10-20% will be in favor
• 60-80% will be on the fence
• 10-20% will be opposed
Changing Organizations
Normal Reactions To Change

- Hope It’s Not Real, “I Can Outlast Them”
- Impact on Me - Lots of Questions
- Fight It - Passive or Blatant
- “Prove It to Me”
- Support It
- Embrace

Changing Organizations
Resistance

- Resistance comes in different forms
- Don’t take it personally
- Some will never accept
- Resistance is not necessarily bad

Changing Organizations
Fear of Losing

- Organizational Change
- Job Focus
- Reputation
- History
- Passion
- Friends
- Respect
- Prestige
- Connection
- Competence
- Culture

Changing Organizations
Why Change Fails

- Misunderstandings
- Power plays
- No “say” In process or outcomes
- Self interest overrides everything
- Fear of the unknown

Changing Organizations
Communication Guidelines

- Need champions
- Talk to people in person
- Tell the truth
- Let people express their feelings
- Discuss the real issues

Changing Organizations
Action Plan

- Describe the change completely
- What is the best possible outcome?
- Timetable
- How will we recognize success?
Focus Groups

- Individuals
- Families
- Board of Directors
- Staff at All Levels
- Community Members
- Funders

Outcomes defined by people with disabilities and their families:

- Home
- Work
- Friends
- Money
- Volunteer
- Safety

The New Focus Is...

Why Study The Future?

- No one knows what will happen
- Opportunities as well as danger
- Change needs to be constructive

Changing Organizations

Becoming A Learning Organization

- Learning Organizations take risks
- Learning Organizations partner with individuals who will challenge them
- For every person considered “too disabled” to work, someone somewhere has figured it out for a person with similar needs

Changing Organizations

Becoming A Learning Organization

- Every improvement in services for people with severe disabilities has been a movement away from institutions and segregation and toward community and inclusion
- Learning Organizations need leadership to move toward building social ties.

Changing Organizations

What Learning Organizations Do

- Relentlessly upgrade their team
- Use every encounter as an opportunity to evaluate, coach and build self-confidence.
- Make sure people not only see the vision, They live it. They breathe it. They own it.
Changing Organizations

What Learning Organizations Do

- Inspire risk taking
- Encourage learning by setting the example
- Celebrate success
- Establish trust with candor

Changing Organizations

Innovation Is As American As Apple Pie

- New products every 30 minutes
- YET, we still have so much technology untouched
- Global World
- YET, we can’t convert sheltered workshops to models for building social capital.
- Computers can Drive Cars
- Yet, we are afraid to tear down brick & mortar to get to outcomes.

Organizational Change

Cultural Guidelines...

For Changing The Way You Handle Change:
- Stop the history
- Don’t wait for instruction
- Don’t Play it Safe
- Try not to break things
- Do what works
- Take initiative
- Take more risks
- Welcome destruction

Changing Organizations

Workforce Issues

- Vision
- Flexible Leaders
- Think Strategically
- Retain Best Employees
- Information Age
- Mentor Staff
- Balance Risk with Safety

Changing Organizations

Rethinking Our Policy

- Control
- Choice
- Dignity
- Rights
- Personal Goals
- Self- Advocates as Policy Makers
Changing Organizations

**Funding**
- Free up funding – unbundling - individualized
- Grants
- Fundraising
- Kickstarter
- Collaboration

**Being a Bridging Organization**
- Ask yourself.... What can you do?
- Making local connections with, and advocating for;
  - Transport
  - Housing
  - Employment
- What do you have to contribute to your area? Become a resource...
  - Fundraising
  - Meeting space
  - Partnerships

**Supports**
- Supports should be in the background not the forefront.
- Look for staff who have skills in making connections.
- Creating – supporting – sustaining – exiting
- Find out what is going on out and about
- Get to really know the people you support
- Understanding and empathy – seeing the gifts in people

**What next?**
- Research new practice – stay inspired
- What once was thought not possible – is now possible.
- See challenges as opportunities
- You have the opportunity to change the ideas of disability.

**Shared Leadership**
Make the journey together....
- People to whom you provide support services
- Families
- Support staff
- Community partners
- Anyone else?
Changing Organizations

What next?

“A freely given relationship is the most valuable experience we can have.” “It keeps us healthy and happy in a way nothing else can.”

Learn from mistakes and build on successes

Be guided by creativity and imagination

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OCT 20-21
St. Louis, MO

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OUTCOMES:
The Gateway To Quality

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2015 CONFERENCE
THE DIGNITY OF RISK

What if you never got to make a mistake?

What if your money was always kept in an envelope where you couldn't get it?

What if you were never given a chance to do well at something?

What if your only chance to be with people different from you was with your own family?

What if the job you did was not useful?

What if you never got to make a decision?

What if the only risky thing you could do was act out?

What if you couldn't go outside because the last time you went it rained?

What if you took the wrong bus once and now you can't take another one?

What if you got into trouble and were sent away and you couldn't come back because they always remember you're trouble?

What if you worked and got paid $.46 an hour?

What if you had to wear your winter coat when it rained because it was all you had?

What if you had no privacy?

What if you could do part of the grocery shopping but weren't allowed because you couldn't do all of the shopping?

What if you spent three hours every day just waiting?

What if you grew old and never knew adulthood?

What if you never got a chance?

From Linda Stengle's book, "Laying Community Foundations for Your Child with a Disability."
Reference List


Video Clips:

AOL, (2013), Tim’s Place Albuquerque's Service with a Smile | You've Got, https://youtu.be/y6He0FWoFj0, [April 12, 2015]

