



Relationships Ireland's Immersion Conference

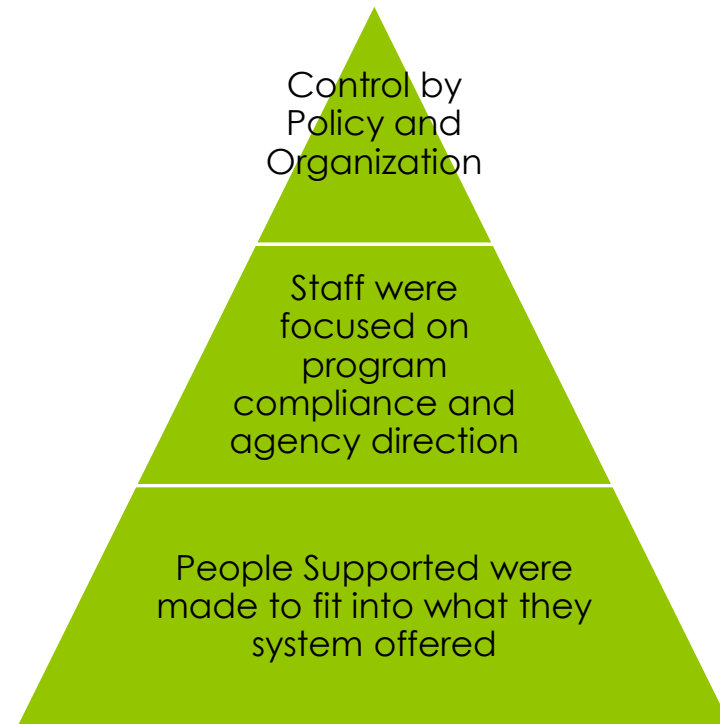
Moving from a Systems
Centered Approach to a
Mindset of Ordinary Lives
and Relationships

The Transformation of a Systems Approach to a Community Approach

System Driven

- People live and work in predetermined buildings
- People have forced relationships
- People's lives are contained within a program
- People are clientized

The Original Hierarchy



Michael

- Michael was put into a forensic center after being arrested many times for assault and fire starting. He was seen to have failed many of the community's group living services. He was determined to be a danger to the community and was not even seen as appropriate for our local institution. He was determined to be one of the 5 most dangerous people to come out of an institution.
 - Answer – The system had rules that he broke. Some rules made him angry and when he reacted he was kicked out of programs. He hurt people and set fire to a group home. INSTITUTIONALIZATION would be all he would have.
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Susan

- Susan lived most of her life in the local institution and moved into the community when a new group home was opened up. Susan was seen to be very challenging and demanding. She would often hit or bite other people and would frequently break windows and destroy others property. She became very agitated when she was left at home and others went out without her. The neighbors did not like her.
- Answer – Continued placement in a group home, along side of a people she did not like.

Paul

- Paul had always lived at home, went to a local church with his family. He knew his neighbors and liked to pick up their lawns. He used to go on contracting jobs with his father. Paul's father developed cancer and his mother could not take care of both of them so she looked for a placement.
- Answer – A new group home was developing on the other side of the city. They were looking for 6 people. Paul was selected.



Our Learning

Factors that Lead to a Lower Quality of Life

Social Isolation

- Labels
- Being misunderstood
- Being identified as group
- TV
- Control by staff
- Mindless supports
- The nature of being a client
- No understanding of life's fundamental needs

Physical isolation

- Nice home/nice neighborhood but knows no one
- Nice place to work but not accepted
- Visits "community" in a "client" world
- Attending "client" activities.

A New Direction

- We needed to draw the parallels between normal life and the lives of those supported
- We needed to change our mindsets
- We needed to ask different questions
- We need to change the control
- We needed to learn to listen

A Deeper Understanding of Basic Human Needs

- Personal Self Control and Direction
- Belonging
- Value and Respect
- Dignity
- Health & Safety
- Home
- Family
- Friends
- Career
- Community Lifestyle
- Full and Rich Life
- Spiritual Well Being

Factors That Lead to a Higher Quality of Life

- Goals
 - For acceptance
 - For relatedness
 - For community feeling
 - For interpersonal relationships
 - For belonging and engagement with others
 - For meaning and purpose

Impact of Services on the Life of Three People

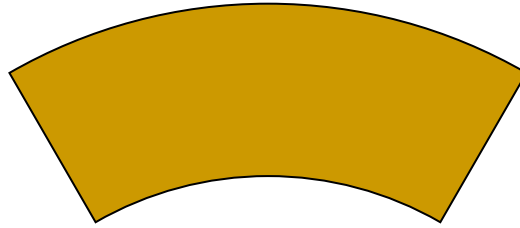
*Mike, Susan and Paul...
and what they taught us*

The Impact of the Wrong Services on One's Life



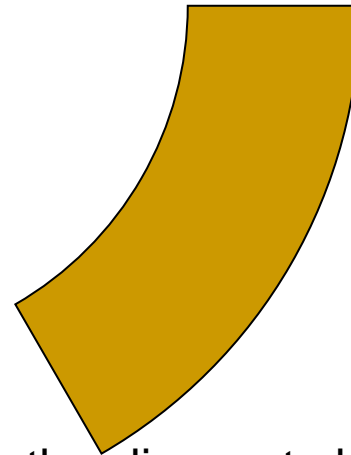
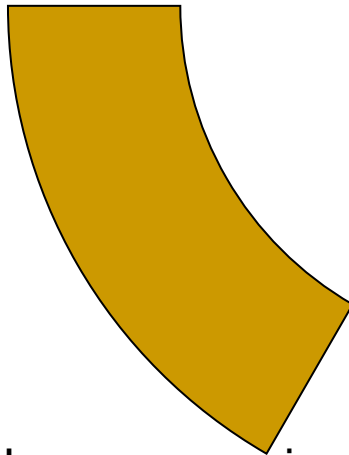
- Models of Support
- Impact on a Person's Life
- Reactions
- Misunderstandings
- Traditional Responses
- Cycle of Negativism.





How we see a person

Is how we perceive a person



How we perceive a person is who they live up to be

Paul, Sue and Mike's Life

- Life was left behind
 - Stripped of home community
 - Stripped of relationships and routines
 - Limited visits with family
 - Living with strangers
 - Living with “sick” people
 - Staffed by people they did not want or choose
 - Unequal relationships
 - Wrong people, wrong relationships
 - Negative use of power and authority
 - Medications, medications and more medications
 - Behavioral programs and restraint
 - Cycle of negativism with no way out.
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Beginning of Changes

- Recognizing the hurt and the losses
 - Questioning the psychiatrist, medications and behavioral control
 - One person seeing the light (Beth, Debbie, Karen)
 - New connections found
 - Community people now involved
 - Anger and hostility better understood
 - Parents and advocates desperately making referrals, trying to figure out a better “program”, or had not other vision that what was then offered
 - Deepened planning sessions.
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Taking the Time to Learn Through Paul, Mike and Sue

- History
 - Lost Routines
 - Lost Relationships or Void of Relationships
 - Lost Places, or Never Had Them
 - Lost Respect and Positive Recognition
 - Loss of Interdependence
 - Lost of Personhood
 - Completely Misunderstood
 - Many Vulnerabilities
 - A person who was seen as living as a “client” in a system
 - A person who was not seen to be able to have “normal” relationships.
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Vulnerabilities

Risk of who Paul, Susan and Mike were and may continue to be, with what to safeguard:

- Menace to society
- Dangerous
- Scary
- Medicated
- Friendless
- Seen as a behavioral problem
- Emotionally distraught, no personal authority, disempowered
- Agitated
- Angry
- Not respected
- Disabled
- Alienated
- Disconnected
- Continued losses
- Lonely
- Stuck
- Staffed
- A Client of a system.

Safeguards

- Help to be understood and heard
 - Help to be more at peace and have more legitimate say and authority in life
 - Open life to friendly relationships
 - Open to real friendships
 - Open life to meaningful life
 - Assistance to be with people who are mutually enjoyed
 - Assistance to become a man or woman with meaning.
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Deeper Understanding

..... of what a new life could become

- No typical staff
 - Community identified
 - Real person, Real life
 - Neighborhood Connections
 - People with Common Interests
 - Good people who each person chooses
 - Own home
 - Regular working, socializing.
-

The Beginning of a New Life

Realization of what action that needs to take place



- Listen...listen...listen
- Establishing a life and personal lifestyle
- Finding a house in the identified neighborhood that could be a home
- Finding the people each person values to share life with
- Finding the support people who each person wants
- Reconnecting and expanding life within neighborhood and with family
- Reconnecting and expanding relationships.

Continued Reflection

What is not working

- Paul, Mike and Susan were agitated, dangerous
- Mornings, staff, rules and limitations were difficult
- “Past staff” that were not accepted.

What is Now Working

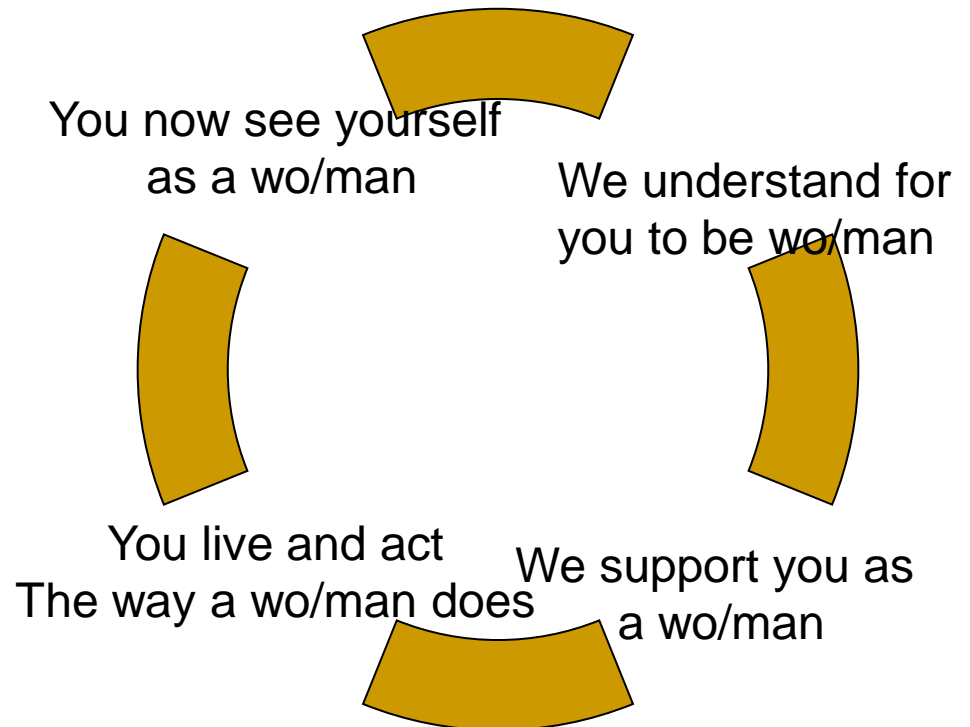
- The home is Paul’s, Susan’s or Mike’s
 - Each person has become more connected in their community
 - Each person has more meaningful home and work
 - Each person is now known and accepted in their community
 - Paul, Mike and Susan reside with people they each value.
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New Knowledge with Readjusted Sails

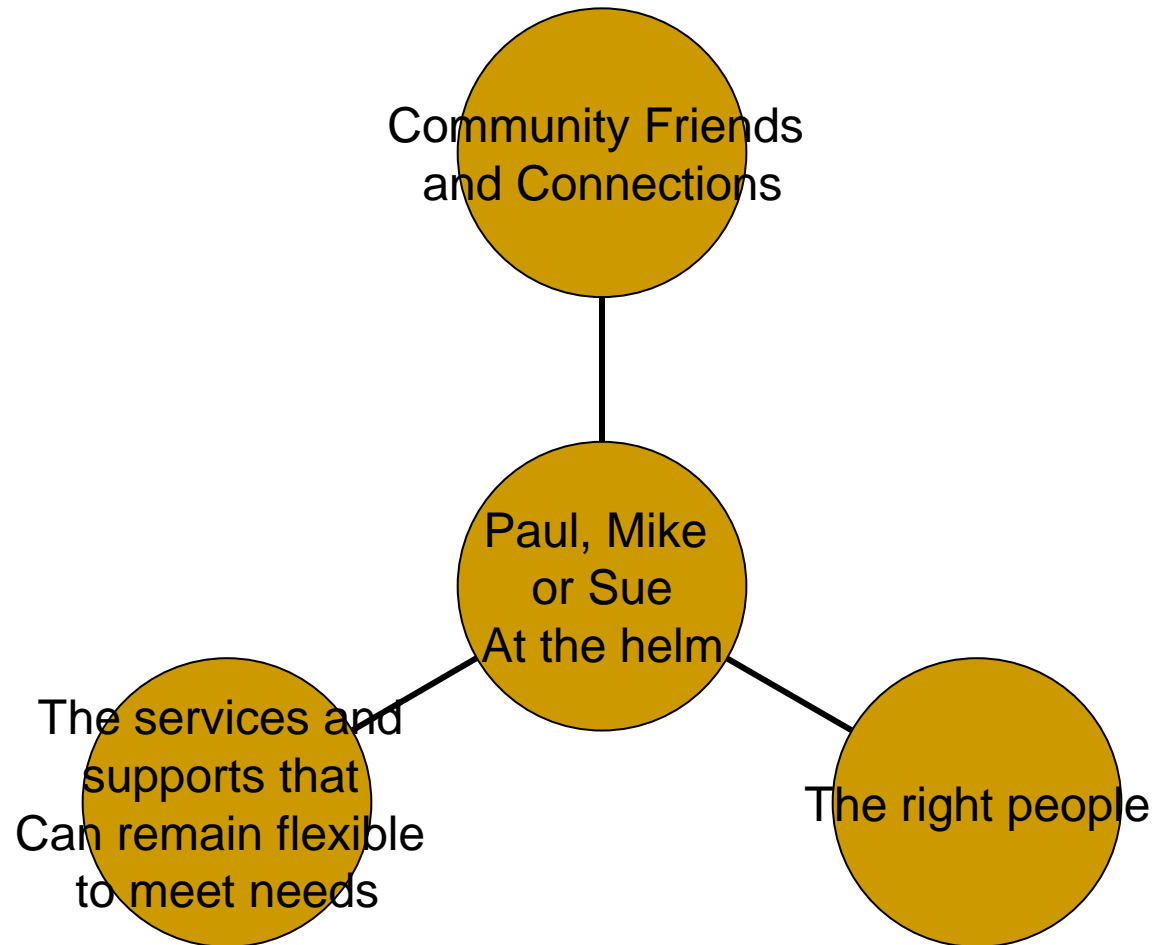
- Trust issues need to be earned and established
 - Learning to put the power to the person, housemates and community friends
 - Medications
 - Further move from the system of control
 - Additional vulnerabilities and safeguards
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- I am a
Person
...not a client

.. I am a person
embedded in
relationships



Each Person's Personal Heading



Mike Today

- Intensive planning, “champion” found job through a connection she had, told us then the neighborhood he would live in, he moved in at first with “two big guys”....with big hearts. Our job at first was to keep him out of jail and institution. Over time he learned to trust himself and we learned to trust him. We decreased support over time down to one housemate.
- He just celebrated 20 years of working in the same place with his co workers
- He and Richard have been living together for 18 years. Going through many experiences that melded them together.

Susan Today

- Sue institutionalized at a very young age. A “champion” thought we could do better. Brought everyone together for intensive planning. Had believers and mostly disbelievers. Took months of planning. Sue high energy and “burns people out”. Mom finally agreed for her to move. Staff from the group home supported her at her new place. It became a one person group home due to the mentality of staff and the reputation they upheld. We had to make changes. Sue had a few different housemates. She got to know Ingrid who was hired as her key worker. They got along well. Ingrid left the agency and later returned as a coordinator and asked to coordinate for Sue. When another housemate decided to move on, someone gave Ingrid the idea for her to move in with her until someone was found. That was 15 years ago. They still reside together. Ingrid has gone through getting married and selling and buying another house and Sue has been with her through all of it.
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World and Life with Continued Need to Refocus for Clarityagain and again



Ongoing Reflections

Questions

- The change in mindset
- The change in what is being asked
- The change in not offering anything
- The change on how we planned
- The constant being stretched
- Being in the community different than being part of community
- Staff role changing from care takers to community connectors.

The Opening Up of Community

- Volunteers vs Relationships
- Embedding a life into community
- Opening up our minds that people can be friends with people
- Changing language
- Changing culture
- Getting out of the way
- Trusting honest relationships
- Not a work site, a home, a job, a social life.

Change of Roles

- Of the organization
- Of the administration
- Of the state government
- Of the families
- Of the friends
- Locust of control changes
- Safeguarding on multiple levels

Programmatic Safeguards

- Respectful language
- Person centered language vs person centered lives
- Seeing each person as a person and not a client of a system
- Believing in the possibility of true community relationships
- Listening without knowing the answers
- Effective supports vs ongoing care
- Recognizing each person for the valued roles they can take of renter, home owner, co worker, friend, neighbor, son, uncle
- Each person's service and lifestyle is unique. No cookie cutter services

Transformational Role of People

- Flexible supports
- Welcoming of community people, family
- Changing supports as each person's needs changes
- No Predetermined structures
- Medications have decreased
- Behavioral supports are now non existent
- Incidents do not happen
- Each person is more connected personally
- Each person is more at peace

The Struggle between the System and Normal Lives

- Regulations
- Mission
- Realistic policies, forms, procedures
- Balancing
- Strong Advocacy
- Parent, staff, administration, government
- Doing the best you can do no matter what



Sustaining Relationships Over Time

Mentorship

- Through reading
- Through consultants
- Through visiting
- Through embedding others into your work
- Through embedding yourselves in the work

If you want to learn

- You have to dedicate yourself
- The place that you work has to be dedicated
- You have to have strong person focused planning strategies
- You have to have strong mission, values and personal ethics
- You have to have strong advocacy to help people to survive

- Pat Fratangelo
Executive Director
Onondaga
Community Living
518 James St, Suite
110
Syracuse, NY
13203 USA
- patfrat@oclinc.org
- www.oclinc.org
- 315-434-9597
extension 203

