April Stein, ME d
Assistant Director of Outpatient Services
Servicenet, Inc
Northampton, Mass

Creative and Collaborative Clinical Treatment Model for People with Intellectual Disabilities

April 11, 2014
Woodbridge Hilton, Iselin

The attached handouts are provided as part of The Boggs Center’s continuing education and dissemination activities. Please note that these items are reprinted by permission from the author. If you desire to reproduce them, please obtain permission from the originator.
Creative & Collaborative Clinical Treatment Model for People with Intellectual Disabilities

A model for Treatment of Individuals with Intellectual Disability and Mental Health Needs

J. April Stein, LMHC
Servicenet, Inc
Northampton, Mass
astein@servicenet.org

Introduction

- Servicenet & the Outpatient ID Clinical Team
  - Outpatient Mental Health Center serving over 4000 people/year in five different clinics of those 450 are people with an intellectual disability
  - State funded residential program for people with ID serving over 300 people in five different areas
  - ID clinical team a dozen outpatient therapists working in three of the clinics
  - Collaboration with the DDS, Vocational & Residential Programs
  - Contract with the State to provide clinical outpatient services to people with ID and their families

Introduction (continued)

• NADD Expertise and Collaboration
  - David Hingsburger, MS
  - Dan Tomasulo, PhD
  - Karyn Harvey, PhD
  - Dan Baker, PhD
  - Dale Monroe, LICSW
  - Julie Brown, LICSW

Case Study

• The Story of Bill
  - History of abuse (including sexual abuse) & neglect
  - Trauma
  - Anger
• Individuals in our program have been traumatized, marginalized for many reasons
  - First because of their disability
  - Second by their behavior
  - Self-definition becomes “I am a bad person and I have done something that is bad”

Where we began

• Residential, Vocational and Clinical programs & Funding agencies not communicating
• Staff training stressing containment
• Client’s lives extremely restricted
• On-going maladaptive behavior within the homes
• Treatment model based on behavior plans/medication treatment plans and limited communication between providers
• Families not involved

Etiology of Problematic Behavior

• Counterfeit deviancy (Hingsburger et al 1991) as related to problematic sexual behavior
• Impulsivity
• Cognitive distortions
• Organic syndromes-seizure disorders
• FAS or other exposure to drugs in utero
• Trauma
Traditional Treatment Options

- Nothing, just manage the behavior
- Medicate the behavior
- Behavior Treatment Plans (traditional)
- Contain and isolate
- Time out and restraints

Historical Context

- The late 1970's, when I began my career
  - State run institutional care, “Schools” and “Mental Hospitals”
  - Ricci consent decree in Massachusetts
  - Beginning of community mental health centers
  - Counseling for people with ID
- John Patrick—my first teacher
  - Telling me his story
  - State wide advocate
  - Teaching center in his name

The Boys in The Bunkhouse
Dan Barry, New York Times 3/9/14

- Henry's Turkey Service use of labor from the institution in Goldwaithe, Tx.
- Moved to Atalissa Iowa to the old school house

ID and Mental Health

ID and Psychiatric Disorders

- 1982 Reiss et. al. concept of “diagnostic overshadowing”
- 1983 Sovner & Hurley paper: “Do the Mentally Retarded Suffer from Affective Disorders?”
- 1986 Sovner identified 4 aspects of ID that may influence the diagnostic process
  - Intellectual distortion
  - Psychosocial masking
  - Cognitive disintegration
  - Baseline exaggeration
- Move towards understanding the mental health needs of people with ID and the role in treatment/service provision
- The role of Trauma

Role of Trauma

- Impact of developmental level when Trauma occurs increases impact of the effects of Trauma by disrupting
  - Ability to develop self-regulatory process leading to chronic dysregulation
  - Disruptive behavior
  - Learning disabilities
  - Somatization
  - Distortion in concept of self and others
Role of Trauma

- Conditioned fear responses to trauma related stimuli
  - Loss
  - Change in routine
  - Sounds
- Loss of trust, hope and sense of agency
- Loss of thought as experimental action
- Social avoidance
  - Loss of meaningful attachments
  - Lack of participation in preparing for the future

Trauma

- “Developmental Trauma Disorder” named in children/adolescents.
  - Relevant in describing trauma in people with ID
  - DSM-ID looks at diagnostic criteria for PTSD and adapts for ID
Help professionals look at diagnosis differently and reframe to include the role of trauma (particularly when dealing with Axis II Dx)

Role of Trauma

- Evidence social supports, family history, childhood experiences, personality variable and pre-existing mental Dx; add an ID have increased vulnerability to developing Trauma related psychiatric disorder
- PTSD in people with ID can be triggered by events seemingly benign:
  - Having younger sibling marrying, going to college, obtaining driver’s license
  - Moving to a new home - especially one decided by others
  - Normal life developmental changes
    * Leaving school
    * New job
    * Developing a consensual intimate relationship

Trauma

- Some symptoms exhibited by people with Trauma
  - Cognitive
    - Trouble concentrating
    - Difficulty making decisions
    - Blaming others
    - Memories from past
    - Difficulty talking about the event(s)
    - Poor memory

Trauma

- Trauma informed treatment
  - Change the lens
  - Different way to understand what the client is experiencing

Trauma

- Behavioral
  - Agitation
  - Trouble sleeping
  - Headaches spontaneously crying
  - Recurring nightmares
  - Physical exhaustion
  - Stomach problems
Case Study

- Andrew
  - Sexually abused as a child
  - Foster care system
  - Residential school
  - Reconnection with family
    * Abuse resumes in a different form

Andrew

- Where is the trauma?
- How is it manifesting?
- What could be different?
- Three year follow-up: What happened

Collaborative Model

- Servicenet ID Clinical Team developed a model that is based in clinical foundation
- Success when all elements are incorporated into the whole treatment model
- Communication with entire treatment team is crucial

Underlying Principles

- Problematic behavior is only part of the person should not be sole focus
- Emphasis on action methods rather than cognition alone more useful and long lasting with people who have ID
- People with moderate/severe ID can participate meaningfully with peers who have mild ID
- Empathy for self is as important as empathy for a victim for clients who have hurt others or themselves
- Regular communication throughout the helping system is the key to success
- Family involvement important
- Keep the community and the individual safe

Clinical Foundation for Collaborative Model

- Interactive Behavior Therapy (IBT)
  - A group model developed by Dan Tomasulo, PhD & Nancy Razza, PhD
- Positive Psychology
  - As developed by Martin Seligman, PhD
- Positive Identity Development
  - As created by Karyn Harvey, PhD
- Systems Theory
Interactive Behavior Therapy (IBT)

- Only evidenced-based treatment for people with ID
- Each group session follows predictable format
  - Orientation, Warm-up and Sharing, Enactment and Affirmations
- Predictability reduces anxiety of participants
- Ritualized beginning (orientation) and end (affirmations) provides context for the group's work
- Enactments, uses techniques based in psychodrama, bring individual concerns to life for participants
- Therapeutic Factors

IBT

- Participants identify specific alternative ways to manage their difficult feelings/impulses
- Helps to repair long-standing interpersonal patterns
- Cognitive Networking
  - "social flow" reduces isolation and supports adherence to healthy social norms (Tomasulo, 2012)

Therapeutic Factors

- Acceptance/cohesion
- Universality
- Altruism
- Installation of hope
- Guidance
- Vicarious learning
- Catharsis
- Imparting of information

IBT

- The healing process
  - Correction of the family
    - Finding a voice
    - Being heard
    - Experiencing safety
  - Empowerment
    - Decisions during the process
    - Control in the group
    - Reframing "resistance" as not being "warmed up" to the process

Therapeutic Factors

- Self-Disclosure
- Self-Understanding
- Interpersonal Learning
- Corrective Recapitulation of the Primary Family
- Development of Socializing Techniques
- Existential Factors
**Action Process in Group Work:**

Four Stage Modification

- Orientation
- Warm-up and Sharing
- Enactment
- Affirmation

**The Process and Techniques use in Doubling Includes:**

- Speaking the unspoken (saying what the protagonist isn’t)
- Exaggerating
- Minimizing
- Introducing alternatives
- Restating
- Amplifying (highlighting key part of a statement)
- Verbalizing the resistance (why someone doesn't want to say something)
- Introducing paradoxes
- Clarifying

**Case Example**

- Tuesday afternoon Women’s group
  - Wide range of functioning levels and age
  - Living/working situations vary
  - Changes within the group over time

**Positive Psychology**

- Based on the assumption that mental health symptoms can be treated effectively not only by reducing negative symptoms but also by directly and primarily building positive emotions, character strengths and meaning. (Seligman, Rashid and Parks, 2006)
- Positivity helps people connect with others, develop more resilience for handling challenging situations/emotions
- Grounded in the premise that all people have the ability to change their lives and make positive contribution to the world
- Complements and focuses, does not replace or ignore the rest of psychology

**Positive psychology**

- We have a choice about how we feel
- We can change how we feel
- We can cultivate a sustainable feeling
- We can create and inspire this awareness in others

*Choice, change cultivate and create*
Positive psychology

• What you see in others you strengthen in yourself
  A course in Miracles

  Priming
  Before a staff meeting, clinical meeting, supervision, conjure up the strengths of that person

Positive Psychology

PERMA
Martin Seligman in "Flourish"

Positive psychology

• Flourishing and Well-being
  - Positive experiences
  - Engagement
  - Relationship
  - Meaning
  - Achievement

  - Applies to our clients and our selves

Positive psychology

• Gratitude
  - Reflect on three things to be grateful for each day
  - Gratitude visit/letter
  - Who is the person you would give gratitude to?
  - Case example

Positive psychology

• Kindness
  - Small acts of kindness increases happiness
  - Reflect on act of kindness in the past 24 hours
  - Case example: Invitation to Sally to join the women's kindness group

Resilience

• 2001 Ann Masten "A class of phenomenon characterized by good outcomes despite serious threats to adaptation or development"
• 2004 Bonanno "The ability of adults in otherwise normal circumstances who are exposed to an isolated and potentially disruptive even...to maintain relatively stable, healthy levels of psychological and physical functioning"
Positive psychology

- Post traumatic growth
  - Closely related to resilience

Positive Identity Development

Karyn Harvey, PhD

- Helps people re-imagine the narrative of their lives
- Positive Identity Workbooks
- Draws on principles of Positive Psychology and provides practical applications for working with people who have ID

Positive identity development

- What is needed for recovery from trauma?
  - Safety
  - Connection
  - Empowerment

Positive identity development

- Safety
  - Sense of safety
  - Understanding and responsive staff
  - Food, shelter and emotional support
  - Physical safety from self and others
  - Conversation
  - Safe person
  - Ability to get emotional, social and physical needs met

Positive identity development

- Empowerment
  - Real choices
  - Real input into daily routines
  - Being listened to:
Positive identity development

- Connection
  - Real relationships
  - Listening skills

Positive identity development

- Using the workbooks
  - Who am I?
  - What am I good at?
  - Who are my friends?
  - What do I like?
  - What do I do that has meaning in my life?
  - Where do I make a difference?
  - What am I proud of?

Positive identity development

PERMA
- Positive experiences
- Engagement
- Relationship
- Meaning
- Achievement

Systems Theory

- Family Systems theory was created during the middle of the 20th century when the idea of ecology was borrowed from biology and applied to the study of human problems. Ecological thinking teaches that individual creatures cannot be adequately understood when studied in isolation, but rather must be appreciated within their network of relationships to the other creatures around them if their lives are to make sense.

Systems theory

- Professionalized assumptions regarding need:
  - 1995 McKnight emphasized concerns about the benefits that human service systems gain from creation of "professionalized assumptions of need" and the disabling results these assumptions can have on a client's place in the helping system.
Systems theory

- Three key need based assumptions of professionals and their effects on their client.
  - Need as Deficieny
  - Focuses the deficit on the individual, rather than looking at the more complex, larger system.
  - Client's problems are categorized and separated into professional specializations requiring experts to focus on specific sections. This professional specialization contributes to the development of specialized professional language that is largely unavailable to other parts of the helping system and, in particular, with their families.

Case Example: Ted

- 24 year old man, the only child of a man who worked as a custodian and mother who never worked outside the house
  - CP and in a wheelchair, impaired speech
  - Father wants nothing to do with the helping system
  - Mother balancing between systems
- Father goes to McDonalds every Saturday for dinner with his son
- Entered adult system at age 22, left HS and began work at sheltered workshop
- Long standing complaints that parents did not follow through on medical appointments and follow up treatments (DPPC filings over the years)
- Client cries at his work site saying he wants more freedoms
- State system bent on placing client in shared living (in same town)
  - Buys provider a wheelchair accessible van
  - Provides respite and help making their home accessible.

Treatment Components of collaborative treatment

- Therapists
  - Trained in IBT, Positive Identity Development & Positive Psychology
  - Monthly Skype consultation with Dan Tomasulo
  - Weekly ID Clinical Team meeting
  - Dual role as Individual & Group therapists

Systems

- What ever our role is, we are part of the system
  - Conflicts can become collaborations
    - Priming-what are your colleagues strengths?
    - Shared goals
    - Use of doubling and empty chair as a way to access empathy and understanding of the other viewpoint

Collaborative Treatment

- Emphasis on each staff person's strengths
  - Conflicts can become collaborations
  - Importance for both residential and vocational staff
  - Day to day supervision decisions/support in their residential and vocational programs
  - Helping direct care staff and their attitudes, values and possible personal trauma
  - Emphasis on each staff person's strengths

Vocational/Residential Direct Care Staff

- Staff Training/Support
  - Monthly consultation with the Outpatient clinician
  - Shared language
  - Important for both residential and vocational staff
  - Day to day supervision decisions/support in their residential and vocational programs
  - Helping direct care staff and their attitudes, values and possible personal trauma
  - Emphasis on each staff person's strengths
Family

• Integrate into treatment as much as is possible
  - Support families in maintaining relationships with their family member
  - Family therapy/consultation as indicated
  - Their engagement can be central in their family members growth

Family

• Often the family member(s) not available are the most important
• Use of gratitude visit
• Use of empty chair

Case Management

• Case managers are representative of the state funding agency
• Important members of the treatment team
  - Open communication with all providers
  - Understanding of the clinical underpinnings

Monthly Consultation Team

• Meetings include:
  - Clinicians from residential & vocational programs
  - Residential program director(s)
  - Treating therapist(s)
  - Case Manager

Monthly Consultation

• Continuity of treatment
• Support/supervision of treaters
• Team process mirroring issues within vocational/residential programs
  - Possibility of team members being inducted into individual’s issues
  - Using each other as a way to think through interventions
• A forum for self-care & providing support to direct care staff

Summary

• Collaborative treatment as a model based on Positive Psychology, Action Methods, and on-going Integration of all elements
• What happened to Bill?
Thank you

- Peter Bott, LICSW
  - Group co-leader, therapist
- Marie Hartwell-Walker, EdD
  - Psychologist Franklin/Hampshire Dept. of Developmental Services
- Maureen Biggar, MSW
  - DDS Service Coordinator
- Jessica Newman, LICSW
  - Clinical Director Residential Program
- Amanda Sprage
  - Clinical director Residential Program
- Bruce Eggleston, PsyD
  - Clinical Director Vocational Program
- Earl Uprichard, Tara Boucher & Patrick Chartrand
  - Residential Program Directors