The Universal Precaution of Trauma-Informed Care: Making Sure Each Individual Feels Safe and In Control

Julie P. Gentile, M.D.
Professor of Psychiatry
Wright State University
Dayton, Ohio
Objectives

• Ohio’s Coordinating Center of Excellence in Mental Illness/Intellectual Disability
• Ohio’s Telepsychiatry Project for Intellectual Disability
• Trauma Informed Care
Ohio’s CCOE in Mental Illness/Intellectual Disability

• Coordinating Center of Excellence in Mental Illness/Intellectual Disability
• Initiated in 2004
• Grant Funded Project:
  – Ohio Dept. of Developmental Disabilities
  – Ohio Dept. of Mental Health and Addiction Services
  – Ohio Developmental Disabilities Council
Ohio’s Coordinating Center of Excellence in Mental Illness/Intellectual Disability

• Assessment Capacity
• Educational Programming
• Dual Diagnosis Intervention Teams
<table>
<thead>
<tr>
<th>Community Development</th>
<th>Education</th>
<th>Assessment and Consultation</th>
</tr>
</thead>
<tbody>
<tr>
<td>→ 38 Dual Diagnosis Intervention Teams developed</td>
<td>→ 19,877 education attendees</td>
<td>→ 872 provided ongoing psychiatric care</td>
</tr>
<tr>
<td>→ 60 counties covered by Dual Diagnosis Intervention Teams</td>
<td>→ 51,624 education contact hours</td>
<td>→ &gt;150 new assessments annually</td>
</tr>
<tr>
<td>→ &gt;18,000 inquiries on the CCOE website</td>
<td>→ 354 programs directly sponsored, co-sponsored, and/or with CCOE partners providing educational programming</td>
<td>→ Regional assessment backup clinics in the CCOE network</td>
</tr>
<tr>
<td>→ $382,646 mini grants awarded to local communities</td>
<td></td>
<td>*Access Ohio Mental Health Center of Excellence..........................................................<strong>Dayton, Ohio</strong></td>
</tr>
<tr>
<td></td>
<td></td>
<td>*Nisonger Center (The Ohio State University)..............<strong>Columbus, Ohio</strong></td>
</tr>
</tbody>
</table>
Ohio’s Telepsychiatry Project for Intellectual Disability

- Prototype from 2005-2011 treating 90 individuals from 23 counties
- Telepsychiatry services initiated in 2012
- Virtual software which abides by patient privacy guidelines
- As of December 2013, 254 individuals from 44 counties engaged in the project
- Prioritize individuals from Developmental Centers and State Psychiatric Hospitals
Ohio’s Telepsychiatry Project for Intellectual Disability

- Required Criteria for Individuals Referred
- Child or adult with co-occurring mental illness/intellectual disability
- Medicaid Enrolled
- Self/Parent/Guardian consents and agrees to participate fully
Ohio’s Telepsychiatry Project

• In rural communities ~50% of mental health care is provided by primary care physicians.
• Patients may have to travel long distances or forgo such services altogether.
• Telemedicine helps disseminate skill set to PCPs.
• Many patients prefer to go to a PCP clinic for appointments as opposed to a MH clinic (decreased stigma).
• Increasing data shows reliability/validity are similar to face to face interaction.
Ohio’s Telepsychiatry Project

• Expectations of County Developmental Disabilities Board
• Arrange staffing/computer equipment
• Accept lead role in coordinating access to emergency services as deemed necessary, to include hospitalization.
• Develop a collaborative relationship with local MH Board in order to best support the person’s full range of MH needs.
Telepsychiatry Project

• Simms et al 2011
• Research shows alliance is not compromised by use of videoconferencing.
• Medium made some patients feel less embarrassed and more able to express difficult feelings
• Clinicians length of time in the field affected their openness to the new technology
Telepsychiatry Project in ID

• Reduction in travel time, costs, ER visits and hospitalizations.
• Not necessary to be ‘tech savvy’
• Established programs use ‘buffet menu’ (phone, Email, MD-MD, MD-patient, etc)
• Cancellation rate/show rate
Telepsychiatry Project
Preliminary Results

- For the first 120 individuals engaged in the program, emergency room visits decreased from 195 to 8 and hospitalizations decreased from 74 to 10 (comparisons are 12 months prior to telepsychiatry use to 12 months post treatment).

- A number of the individuals were discharged from state operated institutions and others were in danger of short-term admission, none of the 120 involved in the project were admitted or readmitted to state operated institutions. This saves the state approximately $80,000 per person per year in support costs.

- Travel costs were reduced in some cases by 68% by not having to travel distances for specialty psychiatric care.
Aggression: A Behavior

- TRAUMA HISTORY
- Means of expressing frustration
- Learned problem behavior
- Expression of physical pain or acute medical condition
- Means of communication
- Signal of acute psychiatric problem
- Regression in situations of stress, pain, change in routine, or novelty
Aggression: A Behavior

- Dementia
- Loss of independence and/or physical functioning
- Grief and loss issues
- Escape or avoidance of unwanted demands or situations
- Attention seeking
- Self stimulatory behavior
Bio-Psycho-Social-Developmental Formulation

• A complete gathering of information through client interview, discussion with family members and/or caretakers, review of clinical records, and contact with collaborating agencies that leads to a formulation, diagnoses and treatment plan. The goal is to address and understand the developmental needs of the individual in a meaningful way utilizing Trauma Informed Care principles as a universal precaution.
Biological Aspects

- Demographic data
- Medical illness
- Genetic predisposition
- Medications (past and present)
- Substance use
Biological Aspects

- 85% have untreated, under-treated or undiagnosed problems
- worsened by restrictions on care (labs, office visit frequency and length)
- medications used in ways they were never intended, in unsafe ways, with abbreviated monitoring protocols
Communication Issues

- Talk to the patient
- Expressive language vs. receptive language
- Set the stage when appointment begins
- Summarize at the end
Communication Issues

• Observation
• Relatedness
• Expression of Affect
• Impulse Control
• Attention Span
• Activity Level
• Unusual or Repetitive Behavior
Interview Techniques and Considerations

• Sub-vocalizations
  – reflects a strategy to vocalize the thought processes in the individual’s mind (“hearing”) what they are thinking
  – rehearse what is going to be said or to practice something the individual is planning to do
  – These should not be considered stalling tactics or an attempt to lie
  – Not the same as “talking” from person with a psychiatric disturbance (hallucination)
Fragile X Syndrome
Communication Patterns

• Indirect style of verbal expression
• Eye contact/Sitting at an angle
• “Cluttering”
  – How do you feel about going for a ride?
  – Cars run on gas, you need oil, too
Fragile X Syndrome
Communication Patterns

• Avoidance of eye contact
• Echolalia
• Staccato speech
• Unusual response to sensory stimuli
• Fragile X handshake
• Mental Status Examination
• Perseveration (*Automatic Phrases*)
Crystal

- 15 year old female
- Seen in Emergency Department at Children’s Medical Center
- No mental health history
- New onset aggression, refusal to eat
- Appears paranoid
- Rule out Schizophreniform Disorder
Commonly missed medical conditions

- Seizure disorders
- Pain (chronic)
- Pulmonary (Asthma, Dysphagia, Infx)
- Autoimmune disorders
- Reflux (GERD)/Constipation
- Sleep apnea
- Extrapyramidal Side Effects
- Vitamin Deficiencies
Most Common Causes of Behavioral Problems

• Pain (physical or emotional)
• Medication side effects
• Sleep disorders
• Psychiatric illnesses
Usually NOT Psychosis

• Self-injury
• Explosive aggression
• Phenomena the person can stop or start at will
• Self talk
Interpreting Behavior:
Biting side of hand

• Usually Gastro-esophageal Reflux Disease/(GERD)
• Also: eruption of teeth, asthma, sinusitis, otitis, rumination, nausea, anxiety, painful hands/paresthesia, gout
Interpreting Behavior: Intense rocking

- Not “normal” for the individual with ID
- Visceral pain
- Headache
- Depression
- Anxiety
- Medication side effects
Interpreting Behavior: Head Banging

- This is not “normal” for anyone
- DEPRESSION/TRAUMA HISTORY
- Headache
- Dental
- Seizure
- Otitis/Mastoiditis
- Sinus problems
- Tinea capitus
The world breaks everyone, and at the end, some are stronger at the broken places.

--Ernest Hemingway
Trauma Informed Care

• Research suggests that many people have some form of traumatic event in his or her lives (SAMSHA, 2010). Some experts believe as many as 95% of individuals with ID have some level of traumatic stress. It makes sense to treat EVERYONE as if trauma has possibly occurred. Making sure someone feels safe and in control of their own lives will help someone with trauma, and will not hurt anyone who does NOT have a history of trauma.
“Sit in the chair”

--Jerald Kay MD
Grief and Loss Issues:

Attempt to characterize developmental level and concept of loss/death at that stage
Developmental Implications of Loss and Grief/ Piaget

• Sensorimotor stage
  – Profound ID; developmental age 0-2 years
  – Experience of loss may be one of an expectation that lost object will return
  – Constantly unfulfilled expectation
Developmental Implications of Loss and Grief/ Piaget

• Pre-operational Stage:
  
  – Developmental age 2-7 years
  – Severe/Moderate ID
  – How will the loss affect me? Who will understand me now? Who will take care of me? Who will be my friend? Who will give me things?
  – Fantasy and magical thinking may be used
Developmental Implications of Loss and Grief/ Piaget

• Concrete operations

  – Developmental age 7-11 years
  – Moderate/Mild ID
  – Can understand clear and specific explanations of loss and death
  – Tend to take things literally
TRAUMA

• Normal response: banish it from consciousness
• When the trauma story is told, recovery can begin
• If the story is not told, trauma becomes a symptom
TRAUMA

• Trauma syndromes have a common pathway

• Recovery syndromes have a common pathway
  – Establish safety
  – Reconstruct story
  – Restore connections
Trauma Experience: Mild/Moderate ID

• Will take cues from others’ non-verbal behavior regarding the seriousness of situations and how to respond
• May discount verbal explanations
• May over-estimate or under-estimate the seriousness of situations (knowledge is power)
• Use imagination to ‘fill in the blanks’ when limited or no information is given to them (‘The staff left because of me’)

Trauma Experience: Mild/Moderate ID

• Can experience significant grief/loss reactions, even if loss expected (complicated grief processes)
• Need routine, predictability, and behavioral limits to re-establish feelings of safety and security
   (What/who is home base for you?)
• May imagine illness, injury or pain (physical or emotional) are punishments for past wrong doing
Trauma Interventions: Moderate ID

• Provide concrete explanations for what is happening, what will happen next, and for potentially traumatic sights and sounds in the environment Norwegian ship wreck

• Help identify and label what he/she may be thinking and remind him/her that others feel the same way (“I’m sad”)
Trauma Interventions: Moderate/Mild

• Address distortions and magical thinking and help ‘fill in the blanks’ with realistic information

• Help them create a coherent story to tell others about when happened or what will happen

• Explain and talk about events before they happen; tell them what to expect
Trauma Informed Care

- Manipulating
- Lying
- Stealing
- We can explore these behaviors, determine the underlying meaning and assist the patient in communicating his or her needs more effectively.
Recovery

• Allow patients to save themselves
• Remember what your role is
• Not a savior or rescuer
• Facilitator, support
• Help reinstate renewed control
• The more helpless, dependent and incompetent the patient feels, the worse the symptoms become
The Contract

- Commitment to the future
- Commitment to moving forward
- Commitment to health and well being

- Clarify roles
## Psychotherapy for ID

<table>
<thead>
<tr>
<th>Flexible sessions</th>
<th>Length of therapy sessions should match the individual's attention span. For some patients, this may be no longer than 30 minutes.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Simplification of interventions</td>
<td>Break down intervention into smaller segments and reduce the complexity of the techniques being utilized.</td>
</tr>
<tr>
<td>Adjust language</td>
<td>Reduce level of vocabulary, sentence structure and length of thought to match the cognitive ability of the patient.</td>
</tr>
<tr>
<td>Augment interventions with activities</td>
<td>Use of activities can help to deepen change and learning and may include the use of drawing, therapeutic games, role play and homework assignments.</td>
</tr>
<tr>
<td>Involve caregivers</td>
<td>Important source of collateral information necessary to ascertain progress between sessions.</td>
</tr>
<tr>
<td>Increased length of care</td>
<td>Most research indicates that a longer length of treatment (1 to 2 years) is a best practice with this population. This allows the psychotherapy to move at a slower pace so that the clinician can spend additional time on each intervention utilized, ensuring that the skills being taught are internalized. It also allows for the inclusion of additional treatment stages which may be necessary.</td>
</tr>
</tbody>
</table>
Pharmacotherapy

• Currently no evidence based medicine in the area of dual diagnosed
• Prevalence studies, clinical cases, and side effect studies available
• Consensus-based and practice-based medicine will suffice
Evidence Based Medicine

• Four groups excluded from large, double-blind, placebo controlled trials
• Rationale for exclusion of individuals with ID
• Use timelines
Biological Risk Factors in Patients With DD

- Probable abnormalities in serotonin pathways (varying turnover rate, possibly decreasing circulating serotonin levels)

- Co-occurrence of aggression, depression, and OCD

- High rates of sleep disorders
Consensus Guidelines


- CLINICAL BULLETIN of the DEVELOPMENTAL DISABILITIES DIVISION. *International guide* to prescribing psychotropic medication for the management of problem behaviours in adults with intellectual disabilities. *World Psychiatry Assn 2010*
Summary
Signs the diagnosis is incorrect

• Using more than one medication in the same class
• Residual signs/symptoms
• Use of toxic dosages or presence of side effects
Medications

• Medications prescribed should improve cognitive function (or at least not cause decline)
• Should treat conditions fully
• Should be similar to medications offered to anyone else with the same disorder
Summary

• ID do not protect one from developing MI
• ID do not make one resistant to the effects of psychotropic medications
• Danger of over-diagnosis AND under-diagnosis
• Myth that patients with ID can’t benefit from mental health services including trauma informed care, psychotherapies and state of the art medication regimens
Contact Information:

• julie.gentile@wright.edu
• www.midd.ohio.gov
• www.juliegentile.com
• Julie P. Gentile, M.D.
• Professor, Wright State University Department of Psychiatry