Intellectual Disability-Mental Illness (ID-MI) program

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Clinical Assistant Professor
Co-Director, ID-MI program
Overview

- Development of the program
- Clinical program and outcome data
- Education
- Advocacy
- Research
- REGISTRY
Development of Program

- Dartmouth Master’s in Health Care Delivery Science
  - Alison Lynch, Jennifer McWilliams, Carolyn Turvey
  - Betsy Hradek, Garen Carpenter, Joakim Edvinsson

- Identified top 10 utilizers of psychiatric inpatient services
Program Mission

Improve the lives of adults with ID, MI and CB through clinical care education advocacy and research
Key components

- Interdisciplinary
- Continuity of care
- Patient centered care
- Never give up!

Program Details

- 4-bed inpatient unit
- Outpatient clinic
- UIHC and telehealth
- Education and training
- State-wide advocacy
- Research

IDMI Website
Specialized Inpatient Units in USA

KEY
* - Hospital has two inpatient units
+ - Location has two separate hospitals, each with one inpatient unit

Siegel, 2012
## 6 Studies with Standardized Outcomes

<table>
<thead>
<tr>
<th>Author</th>
<th>Year</th>
<th>Location</th>
<th>Beds</th>
<th>Age</th>
<th>% Male</th>
<th>% Mild ID</th>
<th>% CB</th>
<th>Mental Illness</th>
<th>LOS (days)</th>
<th>Outcome (# of points in time)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Van Minnen.</td>
<td>‘97</td>
<td>Netherlands</td>
<td>48</td>
<td>31</td>
<td>80%</td>
<td>100%</td>
<td>?</td>
<td>?</td>
<td>?</td>
<td>Reiss, Other (5)</td>
</tr>
<tr>
<td>Raitasuo.</td>
<td>‘99</td>
<td>Finland</td>
<td>5</td>
<td>28</td>
<td>70%</td>
<td>78%</td>
<td>&gt;50%</td>
<td>35% Psychotic</td>
<td>88</td>
<td>BPRS (3)</td>
</tr>
<tr>
<td>Tajuddin.</td>
<td>‘04</td>
<td>UK</td>
<td>12</td>
<td>34</td>
<td>68%</td>
<td>94%</td>
<td>22%</td>
<td>25% Psychotic</td>
<td>71</td>
<td>Reiss (3)</td>
</tr>
<tr>
<td>Xenitidis.</td>
<td>‘04</td>
<td>England</td>
<td>*6/?</td>
<td>35</td>
<td>50%</td>
<td>85%</td>
<td>?</td>
<td>52% Psychotic</td>
<td>161</td>
<td>PAS-ADD, TAG, DAS, GAF (4)</td>
</tr>
<tr>
<td>Hall.</td>
<td>‘06</td>
<td>England</td>
<td>*4/16</td>
<td>40</td>
<td>52%</td>
<td>90%</td>
<td>?</td>
<td>42% Mood Disorder</td>
<td>?</td>
<td>TAG, GAF (3)</td>
</tr>
<tr>
<td>Lunsky.</td>
<td>‘10</td>
<td>Canada</td>
<td>15</td>
<td>35</td>
<td>42%</td>
<td>50%</td>
<td>39%</td>
<td>33% ASD</td>
<td>119</td>
<td>ABC, Reiss, GAF (2)</td>
</tr>
</tbody>
</table>

# Meds
- 6 Studies with Standardized Outcomes
Admission Criteria

- Age 18 or older
- Dual diagnosis AND challenging behavior
- Agency or family active part of team
- Current and active living arrangement

Process

- Referral (Marc Hines)
  - ~150 referrals to date
  - Waiting list 25
  - Intake appointment
  - Inpatient unit or outpatient
  - 1+ year follow-up until patient is stable
Interdisciplinary Diagnostic (PhD, MD/PA)

Inpatient
90 patients
102 admission

Outpatient
127 patients
First, determine *WHY*

challenging behavior is occurring?
**Etiology of Challenging Behavior**

- I have a mental illness.
- I need more skills.
- I want ice cream. (tangible)
- I don’t want to work. (escape)
- Pay attention to me! (attention)
- Non-social (automatic)
- I have side effects.
- I have a medical illness.
- I have genetic syndrome (Behavioral phenotype)
Mental Illness

• Increased rates in individuals with ID
  • ~50% (Reeves, 2011)

• What is the relationship between challenging behavior and mental illness

• Lots of opinions
  • Behavioral Equivalent (atypical presentation of mental illness)
    • Strong Association between depression and challenging behavior (Moss, 2000)
    • Lack specificity (Charlot, 2005)

• Challenging Behavior is not a psychiatric disorder and inclusion results in high rates of psychiatric morbidity (Whitaker, 2006)
Diagnostic Manual-Intellectual Disability
DM-ID 2
Numerous studies indicating etiology of challenging behavior is secondary to undiagnosed medical condition and/or side effects from meds

- PWID have HIGH pain tolerance
- Lack of recognition of common medical conditions
- Lack of preventative health care
- Increased Rates of Mortality and Morbidity
- LACK of education of health care providers

Common Conditions
- GI - CONSTIPATION
- Infections
- Seizures,
- Poor dentition
- Fractures, Osteoporosis
- Aspiration Pneumonia
- Hearing and Visual Impairments

‘The person has ID. . . .that is why he/she is acting that way’

Charlot 2011; Sullivan 2006; Lennox 2004
Side Effects

- Polypharmacy is the norm
- Lack of indication is common

Extrapyramidal side effects
- Akathisia
- Dystonia

Anticholinergic
- Cognitive slowing
- Sedation
- Constipation
- Urinary retention

Benzodiazepines
- Sedation and irritability
- Disinhibition

Scheifes, 2016
Behavioral Phenotype

1. PKU/HA (metabolic disorder)
2. Prader-Willi Syndrome
3. Chromosome 15q11.2-13.1 Duplication
4. Rubinstein-Taybi
5. Smith Magenis
6. *Fetal Alcohol Syndrome
7. Tuberous Sclerosis Complex
8. *Down Syndrome
9. *Fragile X
10. 22q Deletion syndrome
11. Angelman Syndrome
12. Williams Syndrome

* Most common known causes of ID

Developmental functioning and skill needs

- Is the behavior developmentally appropriate?
- Is there a specific skill that is needed to help the person be more successful (e.g., communication, relationships)
- Routine or expectations are not clear
Function of challenging behavior

Applied Behavior Analysis (ABA)

• What does the person gain?
  • Positive reinforcement: social attention, items or activities

• What does the person escape from?
  • Negative reinforcement: work, self-care, staff, difficult situations
First, determine *WHY* challenging behavior is occurring?

Then, we *TREAT*
Who are we treating?

• 30 years old (average); 72% Male

• Severity of ID
  • 40% mild
  • 40% moderate
  • 12% severe to profound

• Known Syndromes (~20% of unique pts)
  • Down Syndrome (2)
  • Williams syndrome (1)
  • Fetal Alcohol Syndrome (2)
  • Angelman Syndrome (1)
  • 105 kb duplication of 22.q13.2 involving genes LOC100506679 (1)
  • 6.1 Mb deletion of 2q12.2q13 including genes SLC5A7 (2)
How are we doing?

Pre-Post unit

(9/15-9/17)

- LOS
- Denial Rate

Post-unit

(9/15-9/17)

- Psychotropic Use
- ABC (Aberrant Behavior Checklist)
- Seclusion and restraint use

Denial Rate

Pre: 31%
Post: 0%

<table>
<thead>
<tr>
<th>LOS - Days</th>
<th>Pre</th>
<th>Post</th>
</tr>
</thead>
<tbody>
<tr>
<td>98</td>
<td></td>
<td>26</td>
</tr>
</tbody>
</table>

# Psychototropic Meds

(9/15-9/17)

- Admission: 4.8
- Discharge: 3.7

***P<.001
Aberrant Behavior Checklist (ABC)

*** = p<.001;  ** = p<.01;  *p = <.05;  t = trending

Admit to Discharge

Significant decrease in all 5 subscales

Admit to 1 mo follow up

Significant decrease in 2/5 subscales

Admit to 12 mo follow up

Significant decrease in 3/5 subscales
Huge multidisciplinary initiative
- Culture Change
- Review of Data
- Education/training
- Debriefing

Psy Services, Smith, 2005

...These closures affected every hospital and involved staff from the state mental retardation centers who challenged the long-standing treatment concepts of the hospital system.

This group of workers, using behavioral support principles, helped decrease dependence on the use of restrictive procedures.

Their contributions to this change, at all levels of the hospital system, were invaluable.
Clinical – Next steps

- Extension to the children’s inpatient unit
  - Michael Lind, PhD

- Telehealth extension
  - Child Health Specialty Clinics (Sioux City)
  - Hills and Dales (Dubuque)
  - More coming soon!

- Expand Team
  - Medicine
  - Behavioral

- Obtain more funds for training
Education/Training

- Healthy Relationship Curriculum
  - Maintaining relationships
  - Planning social activities
  - Feelings
  - Meeting people
  - Personal boundaries
  - Dating
  - Conflict resolution
  - Communication
  - First impressions
  - Sexual health
  - Gender differences

- Inpatient units
  - DBT, ABA

- State/community education
  - Safety Care

- Learners
  - Psychology interns
  - LEND students
  - Medical and PA students
  - Residents

- Medical school curriculum
  - Desire Christensen, MD
Advocacy

- DHS Complex Service Needs Workgroup
  - Intensive residential service homes to serve a minimum of 120 individuals

- Expanded Money Follows the Person (MFP)
  - To include individuals hospitalized for 3 months

- Advocate with MCO’s and regions

- American Academy of Developmental Medicine and Dentistry
Research

- Jake Michaelson, PhD
  - devGenes
  - Genetics of Neurodevelopmental Conditions, NIH

- Krystal Parker, PhD
  - Cerebellar Transcranial Magnetic Stimulation and Cognitive Control

- Melissa Lehan Mackin, PhD, RN
  - Friendship and Dating Curriculum
Neurodevelopmental Registry

Department of Psychiatry -- Department of Pediatrics
Center for Disability and Development -- Iowa Neuroscience Institute

Shannon Hampton
is.gd/brain_registry

Demographics, Medical History, GAD-7, SCQ, CBCL

REGISTRY

- DOB, BMI, Ht, Wt
- Head circumference
- Facial Pix
- Diagnosis and Meds
- Opportunistic blood collection
- Labs
- Social and Family history
- Psychological Measures
  - Cognitive (WAIS, WICS)
  - Adaptive (Vineland)
  - ADOS
  - MORE…….

Newborn screens

Iowa Department of Public Health

Iowa test of basic skills

Data for research

Data for clinical care

Epic
Questions?