

Intellectual Disability-Mental Illness (ID-MI) program

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Clinical Professor

Co-Director, ID-MI Program

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Clinical Assistant Professor

Co-Director, ID-MI program

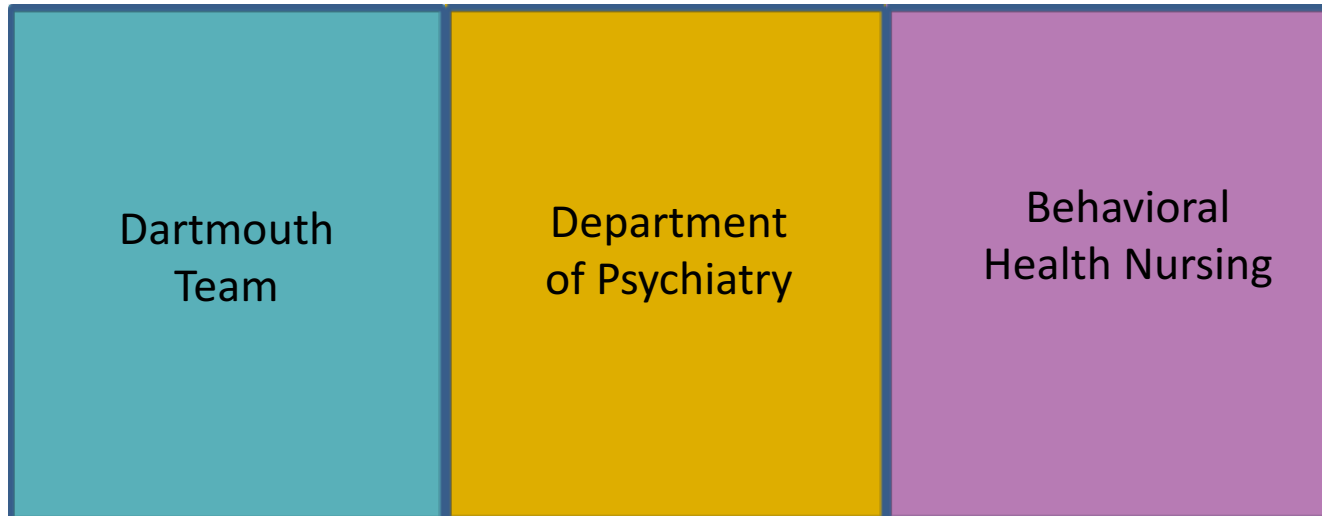
Overview

- 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

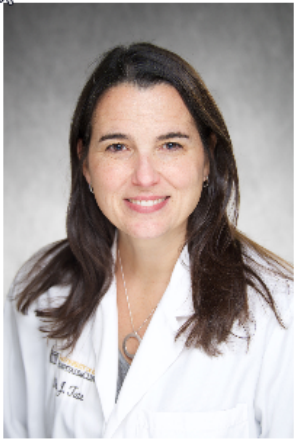


Program Mission

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



Interdisciplinary Team



Jodi Tate, MD



Kelly Vinquist, PhD, BCBA



Alex Thompson, MD, MBA, MPH



Kara Whalen, PA



Ryan Kidder, LMSW

**Inpatient
Staff!!**



Emily Michener, MA, LMHC-t



Marc Hines



Mike L. Ogoli, BSN, RN



Shannon Hampton



Laura Bohnenkamp, MA

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



Specialized Inpatient Units in USA



6 Studies with Standardized Outcomes

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



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

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graph TD; ID((Interdisciplinary Diagnostic  
(PhD, MD/PA))) --> I[Inpatient  
90 patients  
102 admission]; ID --> O[Outpatient  
127 patients]; I <--> O;
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Interdisciplinary
Diagnostic
(PhD, MD/PA)

Inpatient

90 patients
102 admission

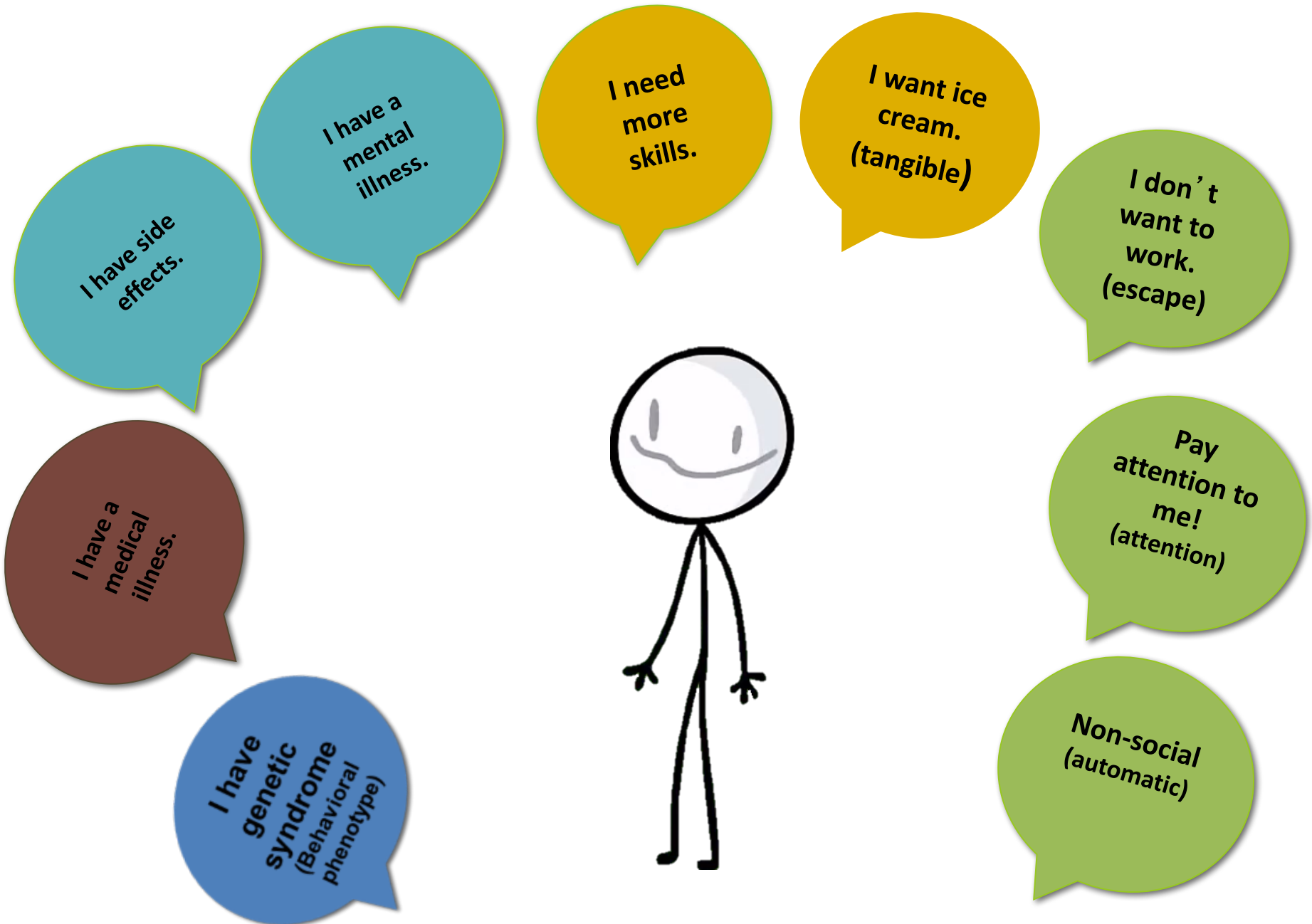
Outpatient

127 patients

First, determine *WHY*

challenging behavior is occurring?

Etiology of Challenging Behavior



Mental Illness

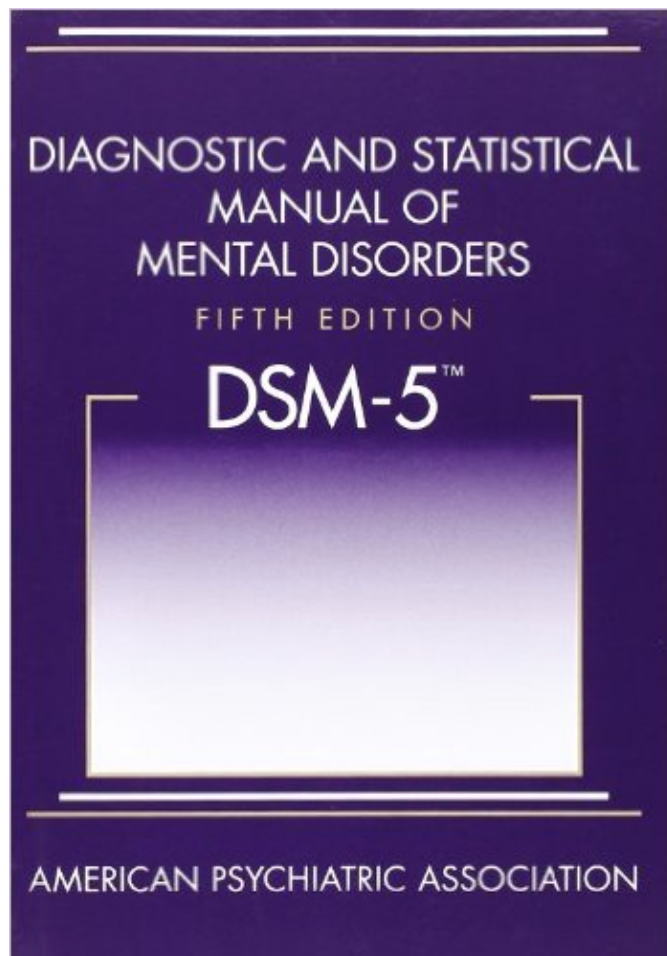
- Increased rates in individuals with ID
 - ~50% (Reeves, 2011)
- What is the relationship between challenging behavior and mental illness



- 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



Medical Illness

- 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

DIAGNOSTIC OVERSHADOWING

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

Side Effects

- Polypharmacy is the norm
- Lack of indication is common
- Extrapyrimaldal side effects
 - Akathisia
 - Dystonia
- Anticholinergic
 - Cognitive slowing
 - Sedation
 - Constipation
 - Urinary retention
- Benzodiazepines
 - Sedation and irritability
 - Disinhibition



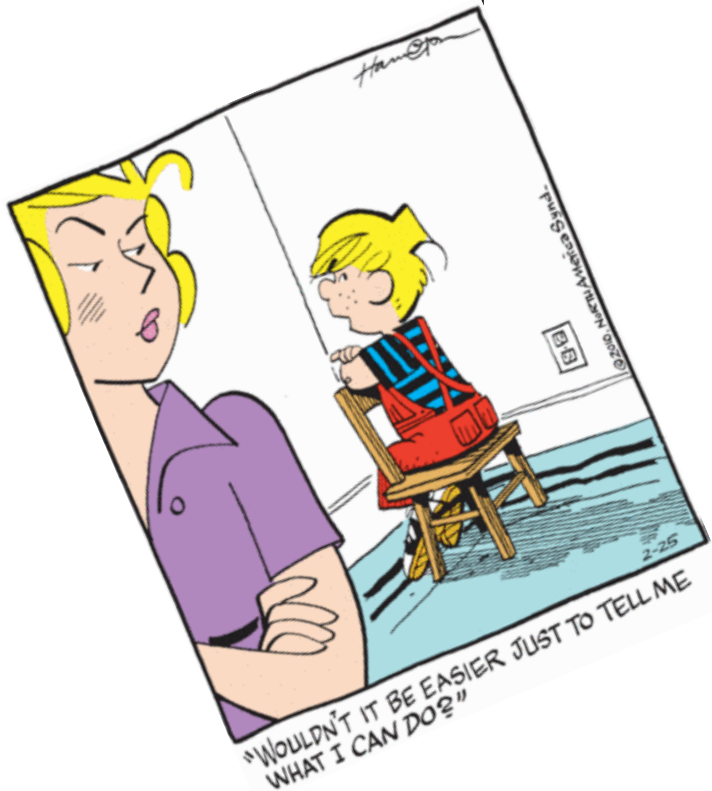
Behavioral Phenotype

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



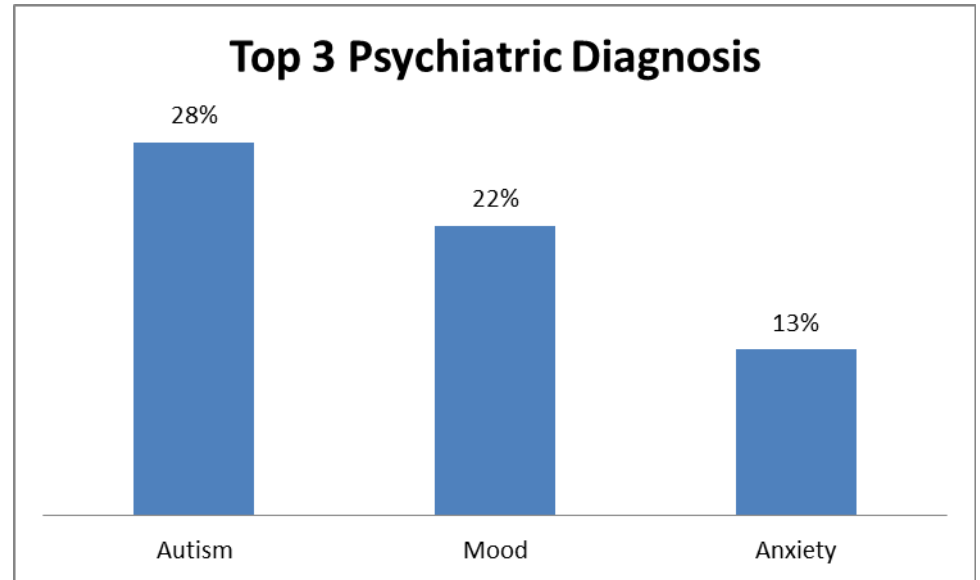
First, determine *WHY*
challenging behavior is occurring?

Then, we *TREAT*

Who are we treating?

- 30 years old (average); 72% Male

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



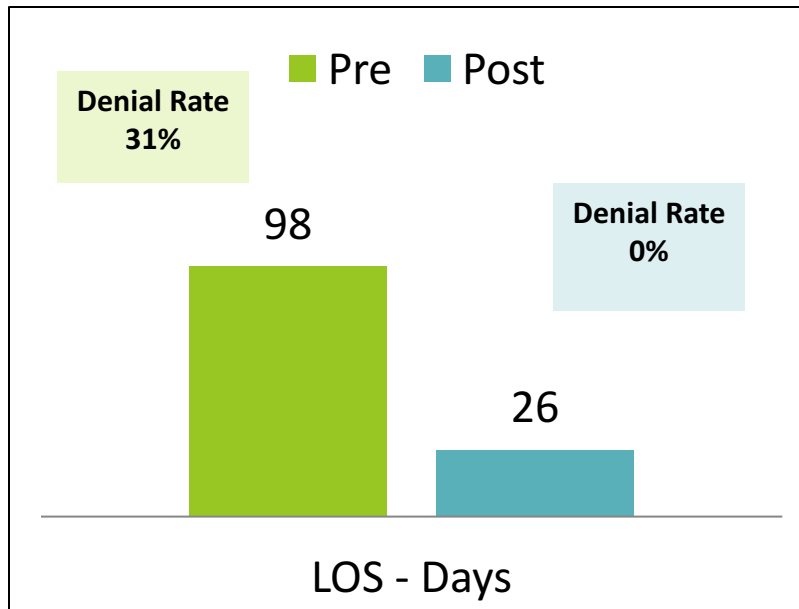
- Known Syndromes (~20% of unique pts)
 - Down Syndrome (2)
 - Williams syndrome (1)
 - Fetal Alcohol Syndrome (2)
 - Angelman Syndrome (1)
 - 105 kb duplication of 22.q13.2 involving genes LOC100506679 (1)
 - 6.1 Mb deletion of 2q12.2q13 including genes SLC5A7 (2)

How are we doing?

Pre-Post unit

(9/15-9/17)

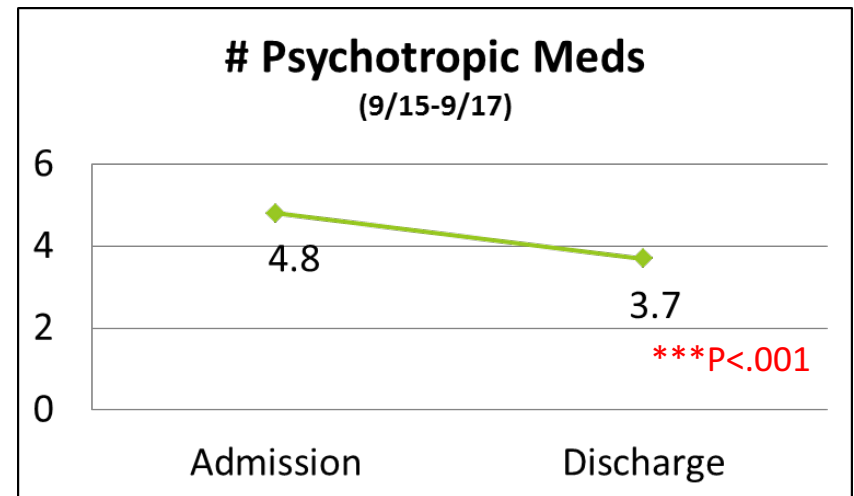
- LOS
- Denial Rate



Post-unit

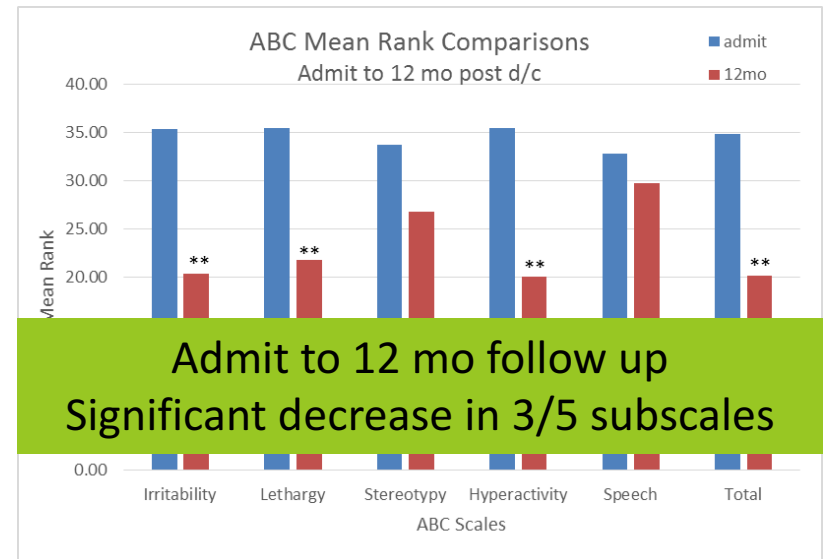
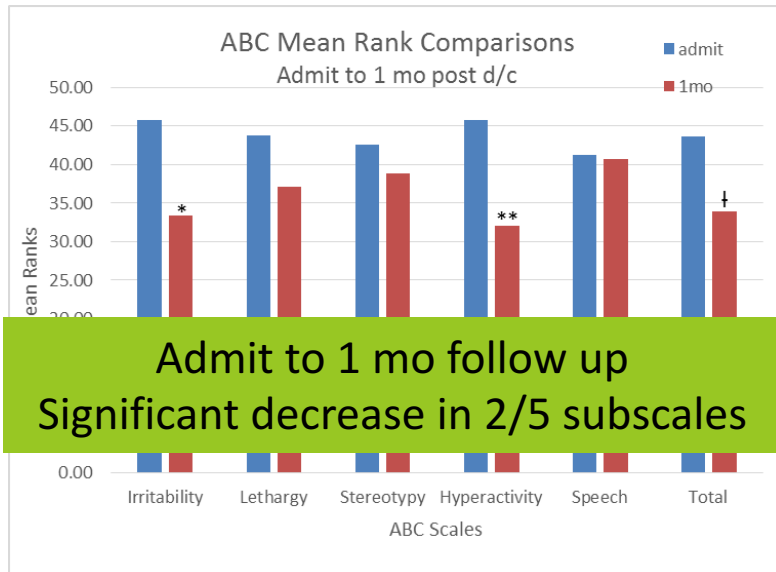
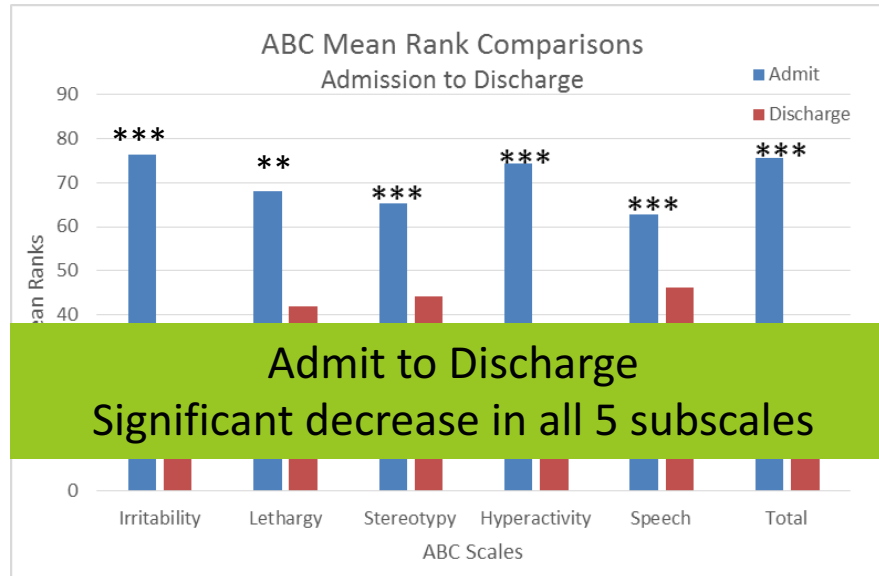
9/15-9/17)

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



Aberrant Behavior Checklist (ABC)

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



Decrease in use of Seclusion and Restraint Use

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.**

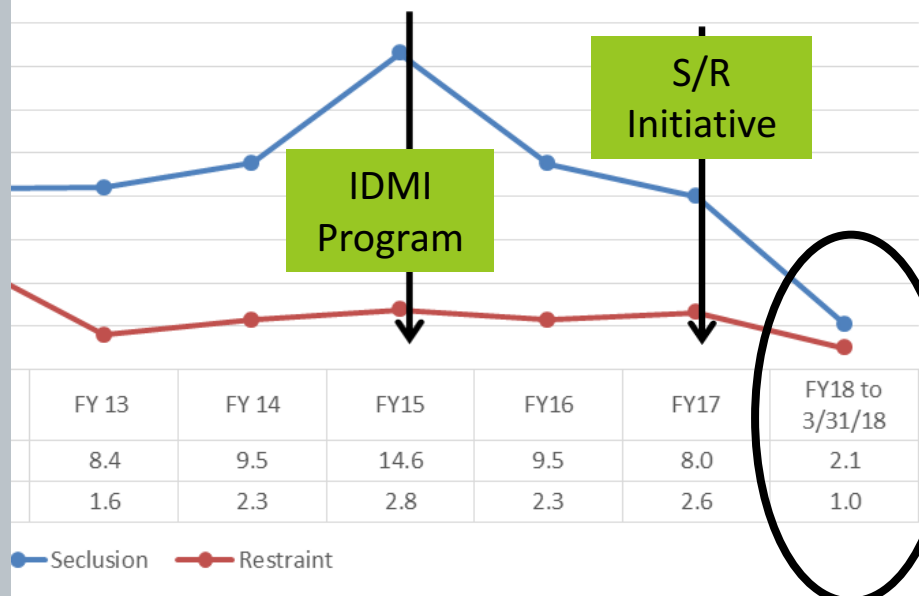
This group of workers, using behavioral support principles, helped decrease dependence on the use of restrictive procedures.

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

Huge multidisciplinary initiative

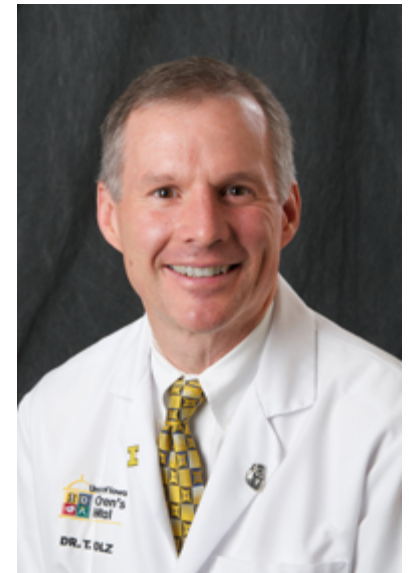
- Culture Change
- Review of Data
- Education/training
- Debriefing

SECLUSION AND RESTRAINT-excluding 3BT
MINUTES PER 1000 PT-HOURS



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

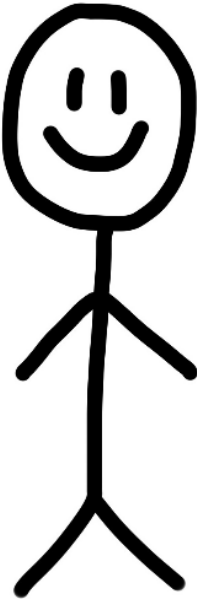
- Cerebellar Transcranial Magnetic Stimulation and Cognitive Control

- Melissa Lehan Mackin, PhD, RN

- Friendship and Dating Curriculum



Neurodevelopmental Disorders at UIHC
RESEARCH --- DELIVERY OF CARE --- CLINICAL CARE



Day Program
Outpatient

Therapy.



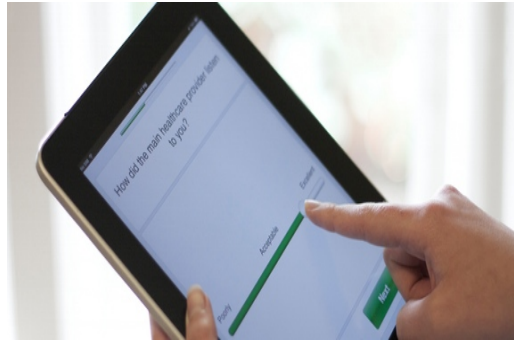
Neurodevelopmental Registry

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



Newborn screens



Iowa test of basic skills



Data for
research

Data for
clinical care

Epic

- 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.....

Questions?

