TRANSITION TO ADULTHOOD FOR INDIVIDUALS WITH INTELLECTUAL DISABILITY

Jodi Tate, MD
Vice Chair of Clinical Services
Co-Director, ID-MI Program
Jodi-tate@uiowa.edu

Objectives

- Understand the changes in funding and support services as adolescents with ID transition to adulthood
- Identify information that should be in the medical record as adolescent patients transition to adult providers
- Understand the role parents/providers of adolescent patients play as their children transition to adult providers

Philip
Born in 1968

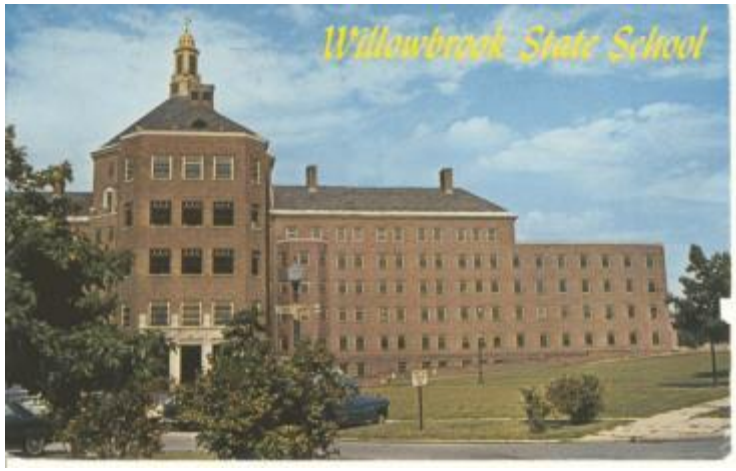
- Philips pediatrician
  - ‘….Contains no oxygen, gives no inoculations, does no operations and administers no ‘miracle’ drugs’

- Joseph Fletcher, Professor and Medical Ethicist
  - “People …..have no reason to feel guilty about putting a Down's syndrome baby away… **True guilt arises only from an offense against a person, and a Down's is not a person**”

Bard B, Fletcher F. The Right to Die. Atlantic Monthly,1968

Willowbrook State School: 1947-1987

- 1972: Michael Wilkins, MD
  - Fired for speaking out
- Public Outcry caused closure in 1987



Things have improved but…
still a **LONG** way to go

- Underserved population
  - AMA, APA, NADD
- 2001 Surgeon General report - goals and action steps
- Lack adequate community services
- High rates of mortality and morbidity

- Lack of training and education of health care providers
- Poor staff attitudes
- Fear of individuals with ID
- Complex health care system

Werner, 2013, McQuistion, 2013

Overview

- Description of ID-MI Program
- Overview of Intellectual Disability
- Transition to Adulthood

ID-MI Program

- 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
  - Telehealth
- Education and training
- State-wide advocacy
- Research

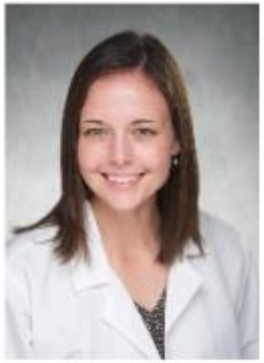
[IDMI Website]

Interdisciplinary Team

Jodi Tate, MD

Kelly Vinquist, PhD, BCBA

Marc Hines



Emily Morse, DO

Michael Lind, PhD

Pixie Plummer, MD

Alex Thompson, MD, MBA, MPH

Kara Whalen, PA

Shannon Hampton

Mike L. Ogoli, BSN, RN

Laura Bohnenkamp, MA

Paul Moseley

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)
- Intake appointment
- Inpatient unit or outpatient
- 1+ year follow-up until patient is stable

Marc Hines

Program Manager

ID-MI Program

Department of Psychiatry

University of Iowa Hospitals and Clinics

319-467-5462

marc-hines@uiowa.edu

We are located on the 2nd level of the John Pappajohn Pavilion, between elevators I and J.

Overview

- Description of ID-MI Program
- **Overview of Intellectual Disability**
- Transition to Adulthood

DSM: MR to ID

DSM-4: Mental Retardation

- Sub average intellectual functioning : an IQ of 70 or below on an IQ test
- Concurrent deficits or impairments in adaptive functioning in at least 2 areas
- Mild, moderate, severe, profound

DSM-5: Intellectual Disabilities: (Intellectual Developmental Disorder)

- Deficits in Intellectual Functions
- Deficits in adaptive functioning
- Onset of intellectual and adaptive deficits during developmental period
- Mild, moderate, severe, profound

Epidemiology

- 1-3% of population has an ID
- 1.5 ♂:1.0 ♀
- > 30% of PWID have mental illness
- Dual Diagnosis
  - Axis I disorder and ID
- 14-30% of PWID receiving psychotropics to trt aggression or SIB **with out** psychiatric dx

ID = Challenging behavior

- 25-50% of people with ID engage in challenging behavior
- 50-75% of people with ID do **NOT** have challenging behavior
- Diagnostic Overshadowing = Assuming challenging behavior is the norm
  - Falsely attributing symptoms to ID
  - Health care providers overlook psychiatric or medical co-morbidity
  - Results in increased morbidity and mortality

Terminology

Feeble Minded (idiot, imbecile, moron)

↓

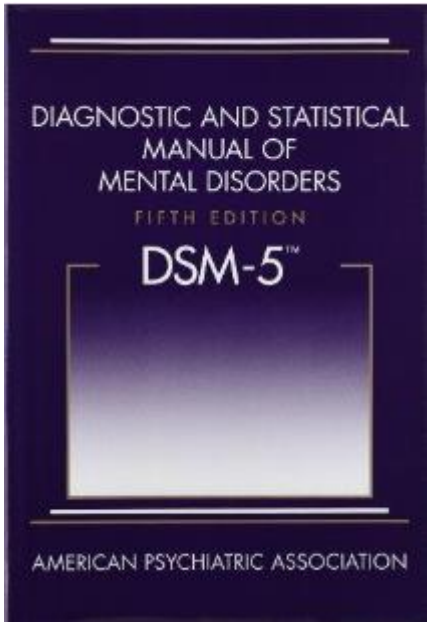
Mental Retardation (MR)

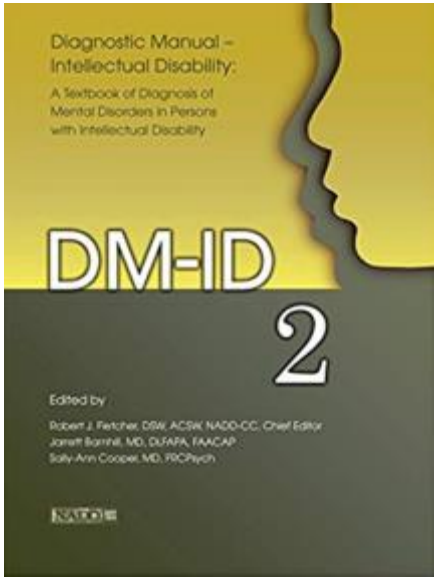
↓

MR/ID

↓

Intellectual Disability (ID)

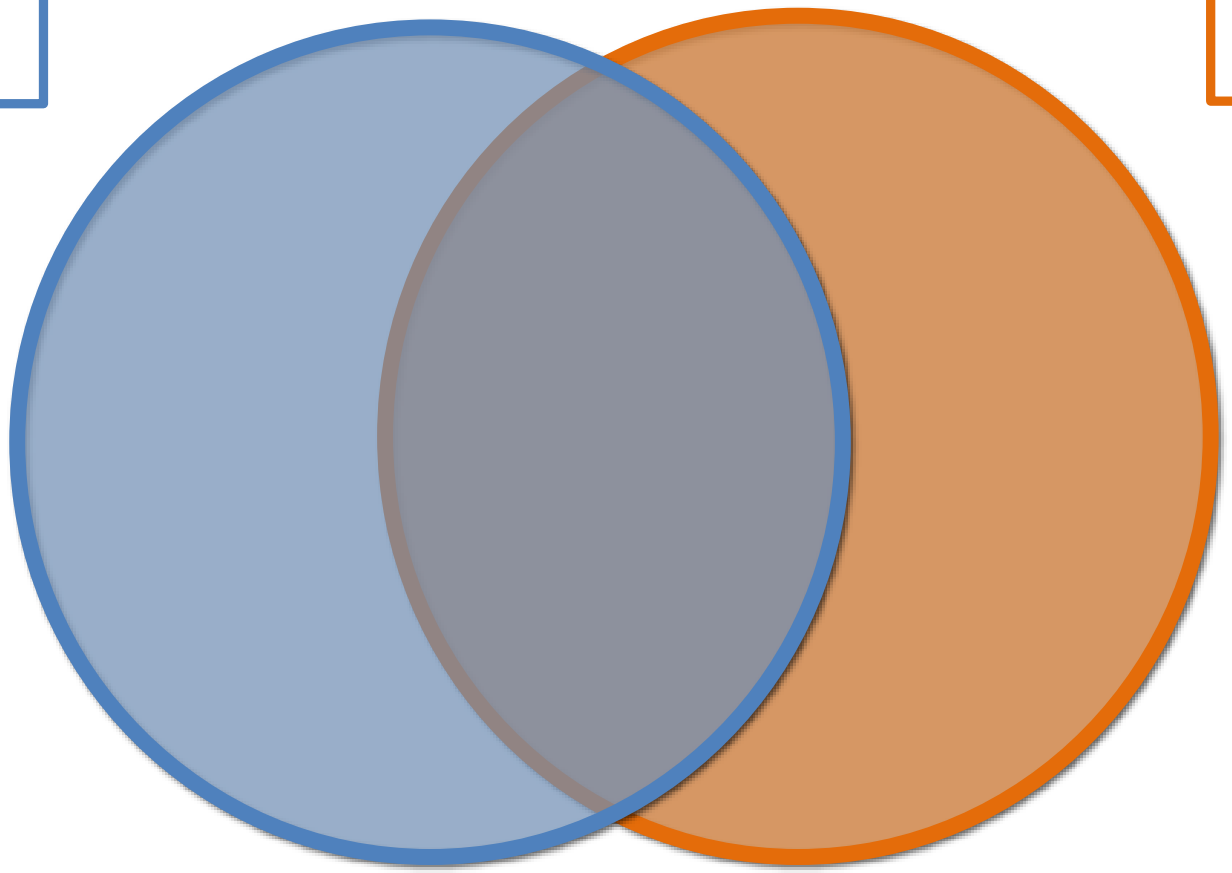




Relationship between ASD and ID

ASD ~ 1%

ID ~ 1-3%



ASD+ID
Strongest predictor of hospital admission, psychotropic use, Challenging behavior

Overview

- Description of ID-MI Program
- Overview of Intellectual Disability
- **Transition to Adulthood**

After age 21 Many Doors Close…..

What happens during transition?

1. Decrease in services
2. Less stimulating services
3. Slowing of improvement in symptoms
4. Increase in Challenging Behavior
5. Increase use of psychotropic medications

Shattuck, 2011; Taylor, 2010; Lovullo, 2011

Decrease in Services

- Increase life expectancy for children with disabilities
- Lack of availability, education and training of adult providers
  - Lots of fears - lack of knowledge, time/$ pressures; family won't stay involved; family expectations
- Pediatric and adult healthcare systems have different cultures
  - Adult system is based on assumption that patients have capacity to make decisions and patients can independently negotiate health care system
- Poor communication between pediatric and adult systems
- Lack of preparation of pediatric providers for transition

Many don't receive adult care until an emergency forces them into the adult system

Kennedy, 2008; Peter; 2019

How can you help?

1. Talk about guardianship
2. Don’t shy away from sexuality
3. Live, work, play, love
4. Support for family/care givers
5. Transition to adult provider

Peters, 2019; Bloom, 2012; Henricks, 2009; Kennedy, 2008

1. Guardianship

- >/= 18 parents no longer in charge of decisions
- Talk with parents about guardianship
- Encourage them to think about this early

2. Sexuality

- Sexuality is ignored and not valued
- Neglected area of education
  - When given often to address problem
- Appropriate sexual activity
  - Rarely taught
  - Restricted and/or Punished
  - ‘needs to be treated’
- High rates of sexual abuse (DM-ID, 2007; NDA; 2011; AAID; 2012)
  - Rate of 80-90% have been reported
  - Often committed by care providers
  - Rarely reported; charges are rare

Myths

- Viewed “Eternal Children” = Asexual

- My child ….
  - is not interested in sex.
  - is not able to control sexual urges.
  - is developmentally delayed so sexuality will be delayed too.
  - can’t be gay.
  - will never have relationships, marry or have children, so learning about sexuality will make them feel left out.

- Teaching my child about sex will encourage them to try it

Friendship and Training Program

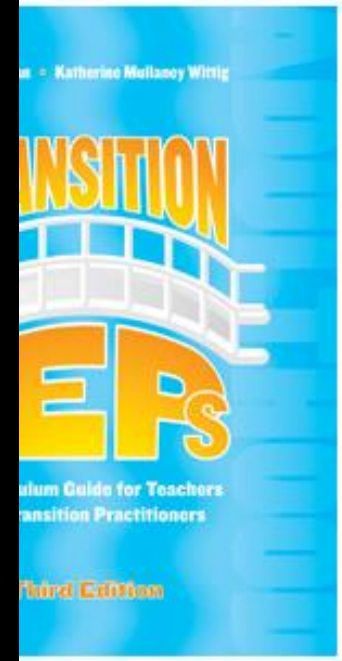
- feelings
- types of relationships
- personal boundaries
- communication
- meeting people
- first impressions
- planning social activities
- the dating process
- personal safety
- sexual health
- gender differences
- conflict resolution
- maintaining relationships

https://www.uaa.alaska.edu/academics/college-of-health/departments/center-for-human-development/friendships-and-dating/index.cshtml

3. Many decisions to be made….

- Where to live?
- Where to go to school?
- Where to work?
- Where to play?
- How to develop relationships?

Up to age 21: Schools provide resources



arning, working

No funding.. No services

ID Waiver

Medicaid funding for individualized supports to maintain community living

https://dhs.iowa.gov/ime/members/medicaid-a-to-z/hcbs/waivers

Where to Live?

- At home with parents/guardians
- Host Home – Private home
- SCL (supported community living)
- ICF (intermediate care facility)

Where to go to School?

- VITAL – Kirkwood Community College
  - Vocational Individualized Training and Learning
  - http://www.kirkwood.edu/vital

- UI REACH Program
  - 2 year transition program
  - 18-25 yrs
  - https://education.uiowa.edu/services/reach

Where to work?

- Workforce Innovation and Opportunity Act – July 2014
  - Goal is to address employment challenges for individuals with disabilities
    - Emphasis on transition services, voc rehab, collaboration
    - Integrated competitive employment is the goal
    - https://thearc.org/wp-content/uploads/forchapters/NPM_WIOA_final.pdf

- Integrated competitive employment
  - Hy-Vee; Co-op; Deluxe Bakery; Olive Garden

- Facility-based employment (sheltered workshops)
  - Goodwill

Where to Play?

THE VILLAGE COMMUNITY

We Are Lions

West music
MUSIC THERAPY SERVICES

513
studio thirteen

Special Olympics
Iowa City Recreation Division

Camp Courageous MONTICELLO,, IA
40 years of serving individuals with disabilties

4. Support for family/caregivers

- Emotional Support
  - Support Groups
  - Respite
- Ensure family is aware of resources

5. Transition to Adult Provider

- Begin discussions early; agree upon a transfer date
- Document
  - Past history including current and past medications
  - Discussions about guardianship, sex ed, plans for work, play, living
- ‘Warm’ handoff– even if it only a few minute discussion
- Get involved with educating new providers
- Develop relationship with adult providers

Transition to Adulthood…

…..is Tough	How to help
1. Decrease in services	1. Talk about guardianship
2. Less stimulating services	2. Don't shy away from sexuality
3. Slowing of improvement in symptoms	3. Live, work, play and love
4. Increase in Challenging Behavior	4. Support for family/care givers
5. Increase use of psychotropic medications	5. Transition to adult provider

Thank you!

Question?