TRANSITION TO ADULTHOOD FOR INDIVIDUALS WITH INTELLECTUAL DISABILITY

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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

- Developmental Disability
- Psychiatry
- Community Agencies
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
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
Overview

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- **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 **without** psychiatric dx
• 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/caregivers

5. Transition to adult provider

Peters, 2019; Bloom, 2012; Henricks, 2009; Kennedy, 2008
1. Guardianship

- $\geq 18$ 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

The Friendships & Dating Program is a preventative program designed to teach teens and adults, 16 years and older, with intellectual and related developmental disabilities how to develop and maintain healthy relationships and prevent interpersonal violence.

- 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
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

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

• Facility-based employment (sheltered workshops)
  • Goodwill
Where to Play?

Combined Efforts Theatre

West music
MUSIC THERAPY SERVICES

513
Studio thirteen

Special Olympics
Iowa City Recreation Division

Camp Courageous
MONTICELLO, IA
40 years of serving individuals with disabilities
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…

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Question?