

Intellectual and Developmental Disability (I/DD)



Community Living and Health Care Experiences

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What does IDD Look Like?



Why is this Important?

- No curriculum for teaching medical students about caring for people with IDD → Unprepared and Uncomfortable Physicians
- People with IDD are on the verge of becoming recognized as an underserved population by federal law - **HEADs Up Act**



Annual Physical Data

- Significantly less cancer screening than general population
- Higher flu vaccination rate
 - Higher risk of infection
 - Less autonomy?
- High incidence of vision and hearing impairment
 - Goal of 100% testing
- Many measures decreased or stayed the same in past 5 years
 - More education needed for physician on how to care for individuals with IDD

	IDD (2011-12)	IDD (2016-17)	General Population
Colorectal Cancer Screening	58%	62%	67%
Flu Vaccine	77%	76%	43%
Has PCP	95%	98%	77%
Dental Exam	81%	82%	64%
Eye Exam (last year)	60%	61%	13%
Hearing Test (last 5 years)	67%	59%	
Mammogram (last year)	62%	58%	67%
Pap Test (last year)	48%	39%	70%
Physical Exam (last year)	90%	86%	20%

Health Disparities

- Overmedicated
 - Especially psychotropic meds
- Common Health Concerns
 - Constipation
 - Dehydration
 - Infections
 - Aspiration pneumonia
 - UTIs
 - Seizures
 - Alzheimer's disease
 - Obesity
 - Diabetes

Reasons for ER Visits

General Population

1. Upper Respiratory Infections
2. Abdominal Pain
3. Contusions (Bruise)
4. Chest Pains
5. Sprains and Strains
6. Open Wound
7. Back Pain
8. Skin infections

9. Fractures
10. Fever
11. Urinary Tract Infection

MA DDS

1. Assessment for possible injury
2. Seizures
3. Upper Respiratory Infections
4. Urinary Tract Infection
5. Fracture
6. G/J tube problems
7. Contusion (Bruise)
8. Sprains and Strains
9. Lacerations/Cuts
10. Systemic Infection
11. Skin Infection

Multidisciplinary Approach to Care

- Occupational therapists
- Nurses
- Social Workers
- Teachers
- Psychologists
- Physical therapists
- Speech and language pathologists
- Physicians
- AND MORE!



Coordination of Care

- Care for children

- Well coordinated care across providers
- Grant funded
- Significantly more resources

- Care for adults

- Far more individualized
- Scarce funding and support

- Barriers to care

- Paperwork and timeline
 - Strict deadlines and stringent documentation
- Dependence on staff to for medications
 - Risk averse
 - MAP program: safe administration of medication to individuals living in community residential programs
- Diagnosis requirements to receive funding/resources
- Lack of entry level workers in MA
 - Recruiting from Puerto Rico and midwest!!
- Insurance
- Trained staff



Health Advocacy

- Department of Developmental Services (DDS)
 - Funding and referrals to state programs
 - Mentor Massachusetts, Seven Hills, assistive technology services, clinical services, etc...
 - Important connecting piece for physicians

- Disabled Persons Protection Commission (DPPC)
 - Mandated reports
 - Important to report even suspicion of abuse
 - Alarming Statistics:
 - More than 90% of people (both male and female) with a developmental disabilities will experience sexual abuse at some point in their lives,
 - Additionally, 49% will experience ten or more abuse incidents.

Health Advocacy cont.

- Other Advocacy Groups

- Special Olympics
- Best Buddies
- American Academy of Developmental Medicine and Dentistry (AADMD)

- Legal Advocacy

- Healthcare Extension and Accessibility for Developmentally Disabled and Underserved Population (HEADs Up) Act of 2019
 - Introduced by Reps. Brian Fitzpatrick (PA-01) and Seth Moulton (MA-06)

Learning through experience

- **Clinical Shadowing:** CANDO clinic, Primary Care, Geriatrics, Developmental Behavioral Pediatrics
 - **What did we learn?**
 - There is a need for more providers who are understanding and happy to care for patients with IDD
 - Communication between providers is critical, especially during the transition period between pediatrics and adult care.
- **Social Services and education:** Seven Hills, State Institutions, NECC, Massachusetts MENTOR
 - **What did we learn?**
 - Physicians are advocates for connecting patients to these services and it is important for students and medical providers to be aware of these resources
 - Physicians to help patients and their families to advocate for resources.
 - Guardianship is an important consideration

Take home points for future physicians

- Talk to the PATIENT first and foremost !!!
 - This is a theme that came up frequently
 - Makes a good first impression
- Listen to the family and support staff who present with the patient
 - They can provide valuable insight.
- Providers as advocates!
 - It can be on an individual level, helping families get the resources they need
- Medical care for this population is changing (slowly)
 - Changes have occurred in large part due to legal action
 - De-institutionalization
 - HEADs Up Act
- Be kind and patient

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- Special Olympics
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- DPPC



Special
Olympics



References

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