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

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

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

<table>
<thead>
<tr>
<th>Reasons for ER Visits</th>
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<tbody>
<tr>
<td><strong>General Population</strong></td>
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<tr>
<td>1. Upper Respiratory Infections</td>
</tr>
<tr>
<td>2. Abdominal Pain</td>
</tr>
<tr>
<td>3. Contusions (Bruise)</td>
</tr>
<tr>
<td>4. Chest Pains</td>
</tr>
<tr>
<td>5. Sprains and Strains</td>
</tr>
<tr>
<td>6. Open Wound</td>
</tr>
<tr>
<td>7. Back Pain</td>
</tr>
<tr>
<td>8. Skin infections</td>
</tr>
<tr>
<td>9. Fractures</td>
</tr>
<tr>
<td>10. Fever</td>
</tr>
<tr>
<td>11. Urinary Tract Infection</td>
</tr>
<tr>
<td><strong>MA DDS</strong></td>
</tr>
<tr>
<td>1. Assessment for possible injury</td>
</tr>
<tr>
<td>2. Seizures</td>
</tr>
<tr>
<td>3. Upper Respiratory Infections</td>
</tr>
<tr>
<td>4. Urinary Tract Infection</td>
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<tr>
<td>5. Fracture</td>
</tr>
<tr>
<td>6. G/J tube problems</td>
</tr>
<tr>
<td>7. Contusion (Bruise)</td>
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<tr>
<td>8. Sprains and Strains</td>
</tr>
<tr>
<td>9. Lacerations/Cuts</td>
</tr>
<tr>
<td>10. Systemic Infection</td>
</tr>
<tr>
<td>11. Skin Infection</td>
</tr>
</tbody>
</table>
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)
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
Special Thanks to:

- Emily Lauer, MPH
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- Roula Choueiri, MD
- Kenia Gomez, PhD
- Seven Hills Aspire
- UMass CANDO clinic
- Special Olympics
- Massachusetts MENTOR
- DPPC
References

- National Core Indicators: https://www.nationalcoreindicators.org/
- Emily Lauer, MPH
- Eunice Kennedy Shriver Center: http://shriver.umassmed.edu/programs/cdder