People with developmental and intellectual disabilities:

community living and health care experiences

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Part 1: Definition of Persons with IDD

What defines Intellectual Developmental Disabilities

- DSM-4: IQ at or below 70
- DSM-5: More holistic view
  - Social skills, ability to perform ADLs, Reasoning, Learning, etc. [1]
- Onset during ‘developmental’ years
- Can occur concurrently w/ physical disability (American Psychiatric Association, 2000)

In 2016 10.7% of Massachusetts residents living in the community had some kind of

Massachusetts Residents by Disability Category (ages 18-64 living in the community)

Disability Category	# of MA Residents	% of MA Residents	% of Disabled in MA
Cognitive Disability	191,579	4.4%	48.7%
Ambulatory Disability	177,389	4.1%	45.1%
Independent Living Disability	148,689	3.4%	37.8%
Self-Care Disability	69,086	1.6%	17,6%
Hearing Disability	68,467	1.6%	17.4%
Vision Disability	62,365	1.4%	15.9%

(MA Rehabilitation Commission, 2016)

How do we address people with IDD?

✕ Don’ts:

- Refer to a person as mentally retarded or handicapped
- Focus only on the person’s disability
- Speak only to the parent/aid/caregiver, ignore the person w/ IDD, act demeaning/condescending

✓ Dos:

- Use PERSON FIRST directives
- Focus on what the person can do
- If speaking to a person w/ IDD:
  - Speak to the person first
  - Use their name
  - Incorporate into conversation & decision making processes as much as possible
- Ask the person how they refer to their condition

Clinically relevant needs

- General
  - Constipation (40%)[2]
  - Mental illness (31%)[2]
  - Epilepsy and seizures (up to 40%)[3]
  - Polypharmacy (up to 40%)[7]
  - Mortality[3]
    - Aspiration pneumonia (19x more likely)
    - Septicemia (3x more likely)
    - Influenza and pneumonia(6x more likely)
- Syndromes (30% of IDD population)
  - Down Syndrome[4]
    - Hearing and ocular problems (up to 50%)[4]
    - Hypothyroidism (15%)[4]
    - premature dementia and Alzheimers (20% by 40, 50% by age 60)[2]
    - Osteoporosis and musculoskeletal disorders[4]

http://md2jupiter.com/the-dangers-of-polypharmacy/

Social Risks

- Legal
  - Guardianship
  - Human Rights
- Sexual health
  - Educate patient on sexual health, STIs, consent, abuse and substance use
- Abuse
  - 60% increased risk of experiencing interpersonal violence[2]
    - Physical, sexual or caregiver abuse
    - Neglect
  - Mandated Reporting
    - *Reasonable suspicion*
    - Disabled Persons Protection Commission (DPPC)
      - Ages 18-59

Disparities

- Access to Healthcare
  - Limited to no formal training for providers
  - Lack of accessible facilities or appropriate instruments
- Poorer health outcomes, mortality, morbidity and quality of life
  - Life expectancy 15-20 years shorter than general population[3]
  - Lower rates of preventative care and screening
    - Mammography (59.6% screened versus 84.9% MA general population)
    - Colorectal cancer (17% screened versus 21% general population)
  - Oral Health
    - 32.2% untreated caries, 80.3% periodontitis, 10.9% edentulism[6]
- Research Gap
  - Exclusion of participants with IDD
  - Few studies focusing on IDD population

Service Project

Massachusetts Department of Developmental Services Adult Screening Recommendations 2017[1] updates to *2014 revision*

The following are global screening recommendations for adults with intellectual/developmental disabilities. There may be other risk factors not identified here. Always consult with the Health Care Provider (HCP).

Procedure	19-29 Years	30-39 Years	40-49 Years	50-64 Years	65 Years +
Health Maintenance Visit	**Annually for all ages.**				
Oral Health Visit	Promote dental health through regular oral hygiene practices, assessment by a dentist at least every 6 months.				
Labs and Screenings					
Cancer Screening					
Breast Cancer	Annual clinical breast exam and self-examination instruction as appropriate		Annual clinical breast exam and self-exam instruction as appropriate. Mammography for high risk patients.	Annual clinical breast exam. Conduct mammography every 2yrs for ages 50+ or more frequently at the clinician's discretion, based on risk factors.	
Cervical Cancer (Pelvic Exam & Pap Smear/HPV)	Screen every 3yrs ages 21-29. When speculum testing is too traumatizing, consider annual HPV testing via vaginal swab.	Screen with Pap test ever three years, or combination of Pap and HPV tests every five years, for women who want to lengthen the screening interval.			Discontinue Pap test after age 65 if there is documented evidence of consistently negative results.
Colorectal Cancer	Not routine except for patients at high risk.			Age 50 (until age 75), select one of the following methods or screening intervals: annual FOBT (Fecal Occult Blood Testing) OR Sigmoidoscopy every 5 years + FOBT every 3 years OR Colonoscopy every 10years	
Testicular and Prostate Cancer	Annual testicular exam for all male patients.		Review screening and testing options for prostate and testicular cancer starting at age 40 for men of African-American descent, at age 45 for all other high-risk men (brother or father diagnosed with prostate cancer before age 65), and at age 50 for all other men.		PSA screening is not recommended for ages 70+
Skin cancer	**Annual screening for those at high risk** (family history of skin cancer, a lighter natural skin color, blue or green eyes, blond or red hair, history of sunbed tanning or sunburns, and people who have taken immunosuppressive medications).				
Additional Recommended Screening					
Obesity	Screen for overweight and eating disorders. Consult the CDC's growth and BMI charts. Counsel on benefits of physical activity and a healthy diet to maintain desirable weight for height. Offer more focused evaluation and intensive counseling for obese adults (BMI>30), or overweight adults (BMI>25), with co-morbidities to promote sustained weight loss.				
Hypertension	**At every medical encounter** and at least annually.				
Cholesterol		Screen with lipid panel men age 35 and older if not previously tested. Screen women age 45 and older if at increased risk for coronary heart disease. Screen every 5yrs or at clinician's discretion. Screen earlier for individuals at increased risk (family history of heart disease, diabetes, tobacco use, hypertension, obesity and use of psychotropic meds).			
Diabetes (Type 2)	**Screen at least every 3-5 years** with the HgbA1c or fasting plasma glucose screen until age 45 for individuals who are at high risk (obesity, family history of diabetes, low LDL cholesterol, high triglycerides, hypertension, sedentary; and for African-, Hispanic-, Native-Americans, Asian).	Screen every 3 years beginning at age 45.			
Liver Function	Annually for Hepatitis B carriers. At clinician's discretion, after consideration of risk factors including long term prescription medication.				
Dysphagia & Aspiration	Screen annually for signs, symptoms, & clinical indicators of possible dysphagia, GERD, and/or recurrent aspiration. Consider swallow study and/or endoscopy as appropriate.				
Cardiovascular Disease	**Conduct annual cardiovascular disease risk assessment**. Specific syndromes and neuroleptic medications may increase risk for cardiac disease.				Screen once for abdominal aortic aneurysm (AAA) in men ages 65 to 75 who have ever smoked.
Osteoporosis	**Consider BMD screening at any age if risk factors are present**. Risk factors include long term polypharmacy (particularly antiepileptic's), mobility impairments, hypothyroid, limited physical activity, Down syndrome, hypogonadism, vitamin D deficiency.			**Consider BMD testing for adults 50+** as most adults with I/DD have risk factors by this age. Repeat BMD testing at HCP discretion.	
Eye Examination	**ALL, including those with legal or total blindness, should be under an active vision care plan and eye exam schedule from an eye specialist (ophthalmologist or optometrist.)** Refer to eye specialist if new ocular signs/symptoms develop, including changes in vision/behavior. **Annual comprehensive eye exam for diabetics.**				
Glaucoma Assessment ophthalmologist/optometrist	Glaucoma assessment at least once by **age 22**. Follow up exam every **2-3 years**; more often for high risk patients		Glaucoma assessment **every 1-2 years ages 40+**, with more frequent eye exams for higher risk patients.		
Hearing Assessment	**Assess annually for hearing changes.** If changes are present, refer to audiologist for a full screen as needed.				

[1] Reviewed sources: Massachusetts Health Quality Partnership (MHQP) 2017 Adult Preventive Care Recommendations; Consensus guidelines for primary health care of adults with developmental disabilities, Canadian Family Physician, Vol.57 2011; US Preventive Services Task Force Guidelines; CDC 2017 Adult Immunization Schedule. Items in **bold** differ from adult care recommendations in order to reflect unique health concerns of people with ID.

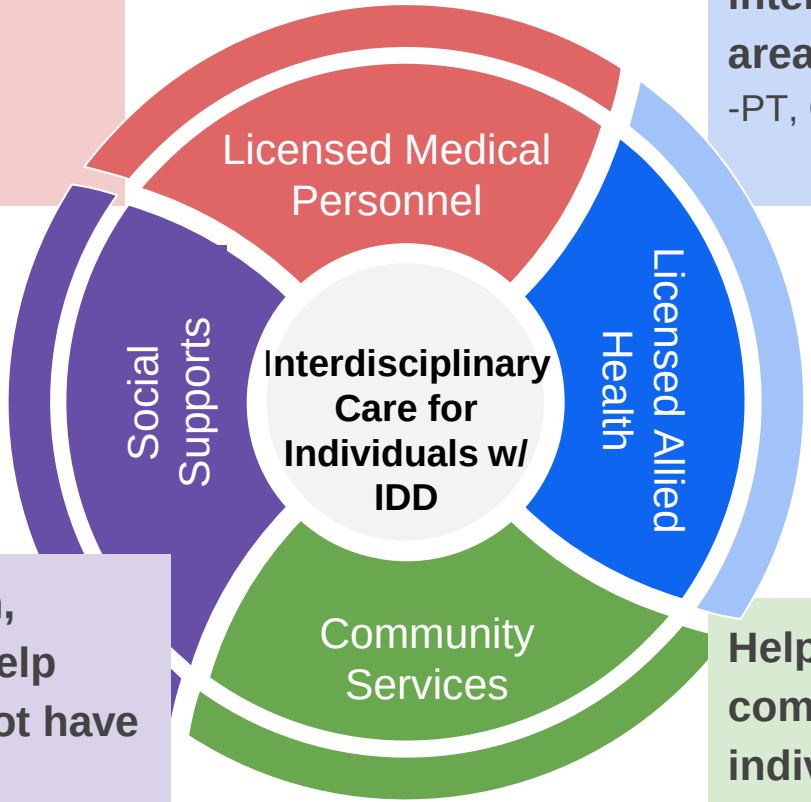
Part 2: Exploration of Interprofessional Teams

Provide medical care including prescribing or administering meds.

-Doctors (Primary Care, Specialists), Nurses, Dentists

Provide therapeutic intervention in a specific area, no meds.

-PT, OT, SLP, Nutrition, Psychology



Provide social interaction, emotional support, and help with ADLs. May or may not have additional training

-UAPs in group homes or day programs*, family, community workers

*Can give meds w/ MAP training

Help coordinate and provide community resources for individual & family.

-Dept. of Developmental Services, Case Managers, Care Coordinators

Interprofessional Teams in Worcester and Greater Boston

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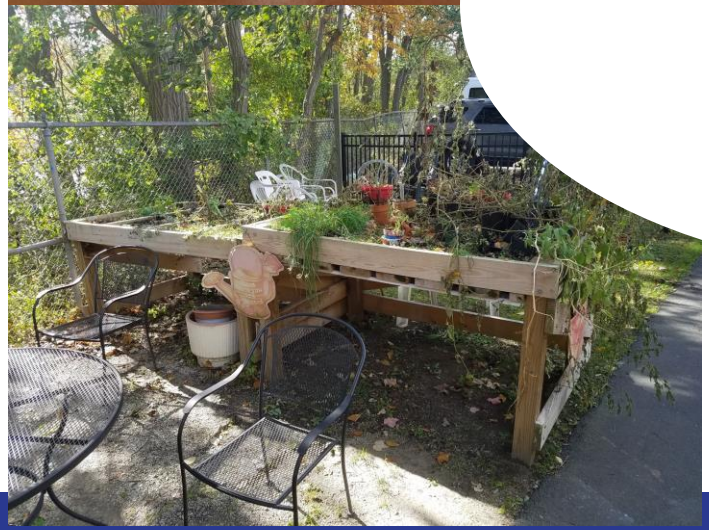
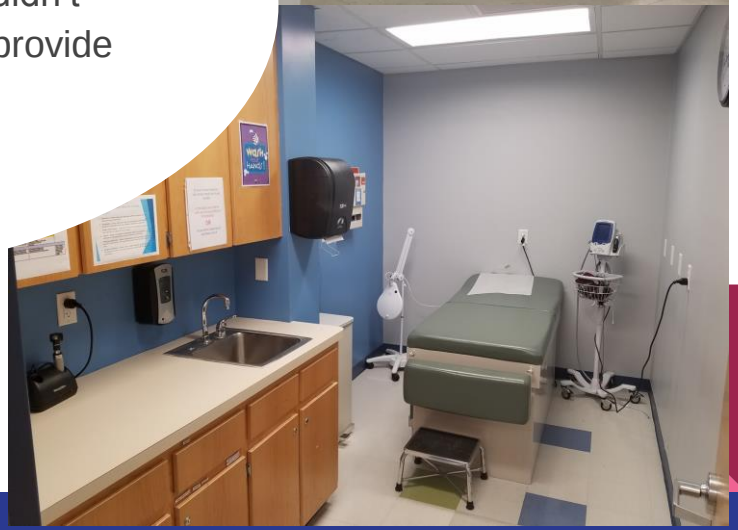
Interprofessionalism is key!

What can these potential team members provide?

- Services that you wouldn't otherwise be able to provide
- Different breadth of knowledge
- Different resources





Part 3: Population Health Advocacy for People with IDD

- On what levels can we advocate?
  - Personal
  - Professional
  - Political
- Largest impact of healthcare changes
  - Lawsuits against the state of MA guaranteed future funding
    - Rolland v. Commonwealth - 1998
    - Olmstead v. LC 1999 - National
    - Ricci v. Okin 1972
- What can we advocate for?
  - Reducing disparities in access to care
  - Improve quality of care
  - “Behavioral issues” are not always expression of disability
  - Communication
  - Longer appointments with adequate reimbursement
  - Funding for IDD community resources (schools, day programs, etc)

Advocacy Groups

Key Takeaways: Areas for Provider Advocacy

The needs of patients with I/DD differ from those of the general population

- Higher risk of aspiration pneumonia/speech and swallow disorders
- Special requirements for the dispensing of medication
- Polypharmacy with severe risk of adverse side effects
  - Constipation
- Speaking to patients directly and listening to caregivers
- Patient transportation
- Patient goals and capabilities
  - Artwork
  - Employment
  - Mobility

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