

Addressing Healthcare Fragmentation for Adults with Intellectual/Developmental Disabilities (IDD) Through Embedding OT in Primary Care

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LEARNING OBJECTIVES

- Describe occupational therapy's role with adults with IDD and how OT services can be expanded to support this population.
 - Describe how occupational therapists can utilize direct and indirect services with adults with IDD, their caregivers, and medical staff to support a comprehensive, interdisciplinary approach to promoting, restoring, and preserving occupational function across the lifespan.
 - Describe the complex, changing needs of adults with IDD as they age and the network of integrated support services such as occupational therapy, behavioral supports, nutrition, psychiatry (etc.) that could enhance health outcomes.
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BACKGROUND

- Adults with IDD face significant health inequities (Mitra et al., 2024; Williamson et al., 2017; Doherty et al., 2020)
 - The proverbial service "cliff" exists at adulthood, where OT and other healthcare supports drop off sharply
 - Primary care systems are ill-equipped to serve this population perpetuating inequities and driving costly, preventable acute care utilization (Williamson et al., 2017; Doherty et al., 2020; Pham et al., 2024)
 - Embedding OT in primary care is an emerging, evidence-informed solution that can support this population (Donnelly et al., 2023)
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EMERGING ROLES : CHANGING FOCUS

Pediatrics

Adulthood

Parent/Caregiver as decision maker

Goals set about the client

Passive client within care team

Often rigid treatment frequency

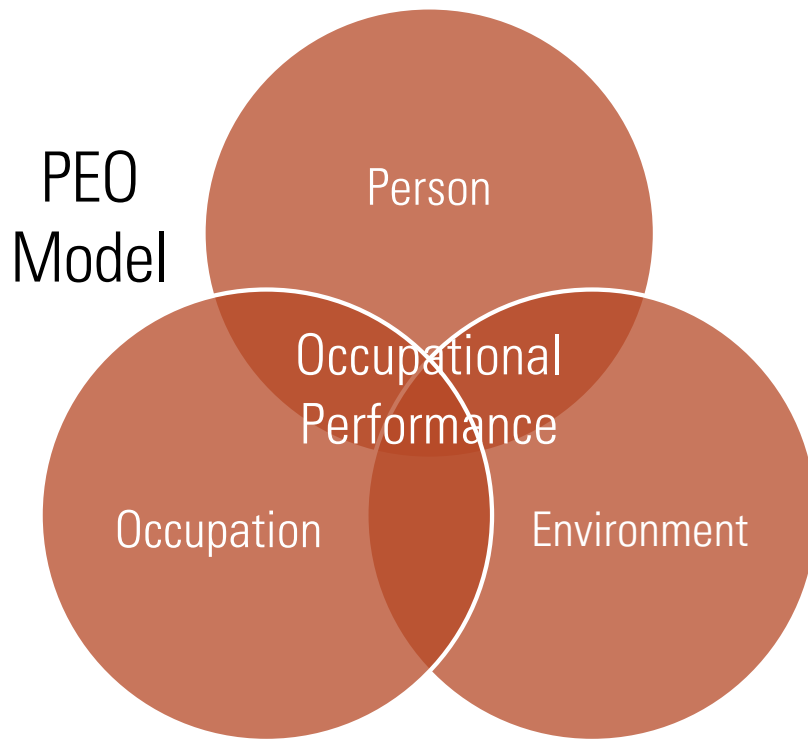
Client as decision maker

Goals set with the client

Active client within care team

Adaptable treatment frequency

FRAMEWORKS AND MODELS



Competence

- People need to gain mastery & control of their own lives and environment.

Autonomy

- People need to feel in control of their own life, behaviors, and goals.

Relatedness

- People need to experience a sense of belonging and connection

Self Determination Theory

KEY DOMAINS



Adaptation/
modification of ADLs
and IADLs



Compensatory
strategies and assistive
technology



Environmental
modification



Transition and life-
course planning



Caregiver/family
education and training



Preserve occupational
performance/ Prevent
secondary conditions



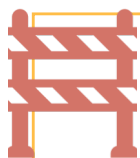
Autonomy in practice:
self-determination



Ability to access OT in
familiar environment



Maintain direct access
to interdisciplinary
supports



Screen for functional
barriers and provide
supports



Decrease costly
reliance on preventable
emergency care



Provide Sensory
Strategies

COMMON REFERRAL DIAGNOSES

- Autism Spectrum Disorder
 - *Developmental Delay*
 - Cerebral Palsy
 - Spina Bifida
 - Rhett Syndrome
 - Intermittent Explosive Disorder
 - *Pervasive Developmental Disorder*
 - Intellectual Disabilities
 - Feeding difficulties
 - Anxiety and mood disorders
 - Language Disorders
 - *Developmental coordination disorder*
 - *Developmental dyspraxia/apraxia*
 - Lack of coordination
 - *Global developmental delay*
 - ADHD
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OTHER COMMON REFERRAL REASONS/ICD-10 CODES

ADL'S

- Impaired mobility and ADLs
 - Other reduced mobility
 - History of falling/high fall risk/increased frequency of falls
 - Self-care/home management training
 - Feeding difficulties, unspecified/other feeding difficulties
 - Need for assistance with personal care
 - Limitation of activities d/t disability (effective 2027)
 - Generalized muscle weakness
 - Other sex counseling/sex counseling, unspecified
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IADL'S

- Need for assistance at home (and no other household member is able to render care)
- Need for continuous supervision
- Obstructive sleep apnea (primary billable code used when managing CPAP/APAP therapy)
- Cognitive communication deficit
- Other problems related to care provider dependency
- Mild cognitive impairment

FOCUSES OF TREATMENT/FREQUENTLY USED BILLING CODES

ADL'S

- Self-feeding (self-care/home management training)
 - Food acceptance d/t impacted nutrition/health (self-care)
 - Dressing/fasteners (self-care/home management training) (therapeutic activities)
 - Executive function to plan, implement (self-care) (TA)
 - Toileting (self-care)
 - Peri care (self-care)
 - Bathing/hygiene/grooming (self-care)
 - Executive function for routine (TA)
 - Functional mobility (neuromuscular re-education) (self-care)
 - Intimacy/sexual health/activity (self-care) (TA)
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IADL'S

- Community mobility/driving (TA)
- Financial management (TA)
- Meal prep/clean up (self-care)
- Housekeeping/yardwork (self-care)
- Religious/spiritual expression (TA)
- Safety/emergency management (TA) (self-care)
- Shopping (TA)
- Caregiving/childcare (TA) (self-care)
- Health management/self-advocacy (self-care)

OTHER BILLING CODES

- Caregiver attendance/training, *initial 30minutes*
 - Caregiver training, *each additional 15minutes*
 - Wheelchair management
 - Orthotic management and training (including custom fabrication assessment, fitting, and training); *initial encounter*
 - Orthotic/prosthetic management and training; *subsequent encounters*
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CASE STUDY

Matteo is a 24 y/o man with cerebral palsy. He lives at home with parents, who are his primary caregivers. He uses a power wheelchair for mobility and uses augmentative and alternative communication (AAC) to communicate. He uses a popover transfer with touching assistance. Matteo recently graduated from his high school transition program and is navigating the shift to adult services.

Matteo's parents are concerned because he is becoming increasingly dependent for ADLS. His parents were unsure how to support his growing desire for independence without compromising safety. They are also concerned about his spasticity becoming worse.

MATEO'S OT SERVICES

- Evaluation
- Intervention

Your turn-- Brainstorm some ideas and talk with a neighbor and we'll share ideas as a big group in a few minutes!



SCRIPTS - EVALUATION

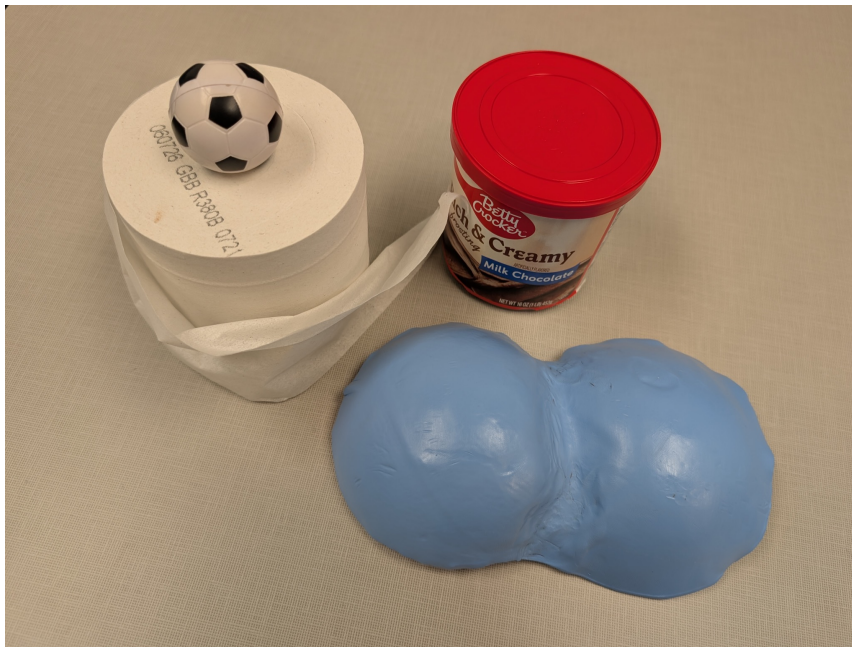


- Providing education on OT in adulthood
 - Prompt: Explain briefly the shift of OT in adulthood (in distinction from pediatrics) for a patient and their team (parents, caregivers, staff, siblings, etc.)
 - Setting expectations for therapy
 - Prompt: How do you present the responsibilities of the therapist, the patient, and their support circle in this context?
 - Wrapping up a plan of care
 - Prompt: How do you explain to patients/team the parameters of discharge or "taking a break" from therapy when there are potentially a myriad of goal areas?
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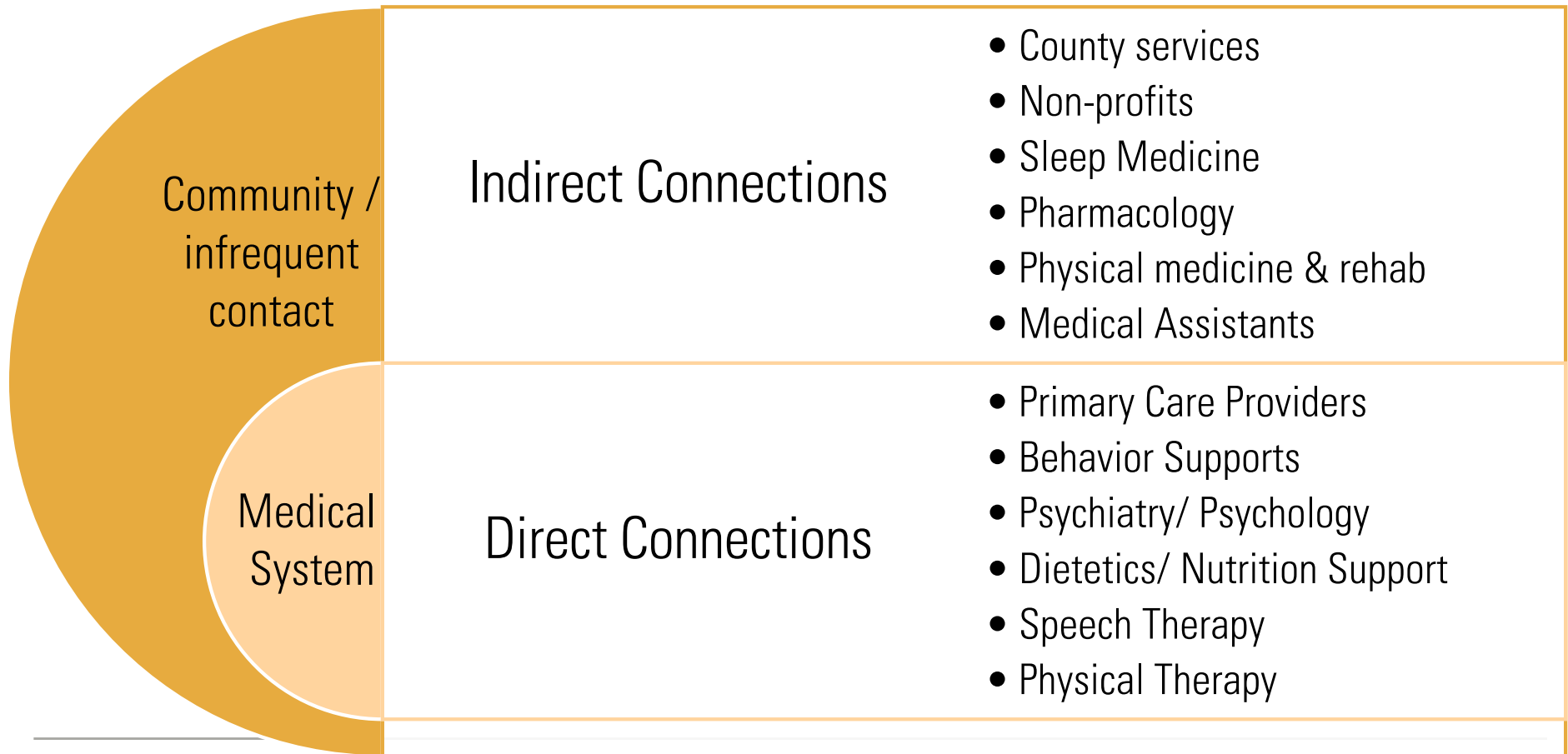
MATEO'S OT SERVICES

- Evaluation
 - Canadian Occupational Performance Measure (COPM) → both client and caregiver if time allows
 - Barthel
 - IADL checklist
 - Modified Ashworth Scale for all affected joints (+AROM & PROM)
 - Sensory Profile
 - Intervention
 - Peri Care
 - Emotional Regulation/Sensory regulation strategies
 - Transfers (Supervision → Independent)
 - Education of community services (community navigator, behavioral health specialists, etc.)
 - Calendar Routine Planning (establish new routines since transitioning out of high school)
 - Establishing an HEP/splinting for tone management
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TREATMENT TOOLS



INTERDISCIPLINARY CONNECTION



ETHICAL DILEMMA EXAMPLES

The Assumed Abilities (or Inabilities)

The External Enticement/Motivators

The “Pushy Parent”

The Rampant Resources

Motivation + Participation

↓ insight
↓ understanding

Strategies:

Educate and help them
connect the task and
ability to importance

Use Task Practice +
Application

“Wonderful
can of
worms”

↓ interest
↓ motivation

Strategies:

Motivational Interview to
find what is important
(intrinsic + extrinsic
motivators)

Start with 1-2 Sessions &
see if motivation sparks
Focus on Compensation

Insight

KEY TAKE-AWAYS

- Follow a path, but let the patient lead
 - What can we do (language, actions, plans of care) to reinforce self-determination and support the patient as the driver?
 - Regardless of resources available, think of the patient's web
 - Rely on your activity/occupational analysis skills -- per occupation, per day, per week
 - Practice your values as a therapist -- *you don't know until you try*
 - Recognize failures and deficit areas, despite trying
 - We can't be proficient in every area; resources fill in where we recognize difficulties
 - Use affect and emotion
 - Share joy, excitement, and pride -- provide connection and value their effort
 - Communicate, share knowledge, and advocate -- disabilities don't stop at 18
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QUOTES

Jason

- "I like coming here because it helps me take care of myself without my staff's help. I like the people here."

Julia

- "(OT has been helpful) by working on and talking about what I need help with; like I can cut my food myself and in appropriate sizes so I don't choke."
- "The uncovering of everyday things that we wouldn't think of that have come up, that we get to work on, and see how things change. It's just great" (Julia's mom)

Lauren

- "Thank you, Tillie!"
- "As Lauren transitioned from her high school programs to adulthood, we lost access to most of her therapeutic services and formal life skills instruction. Having OT available to her as an adult through The Freeman Center has enabled her to gain more life skills that would have been challenging for her in absence of structured therapy services." (Lauren's Parents)

QUESTIONS?



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*Scan QR code to submit
your evaluation*

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