Disability-Inclusive Healthcare Systems

The Arc of Pennsylvania, Lunch and Learn

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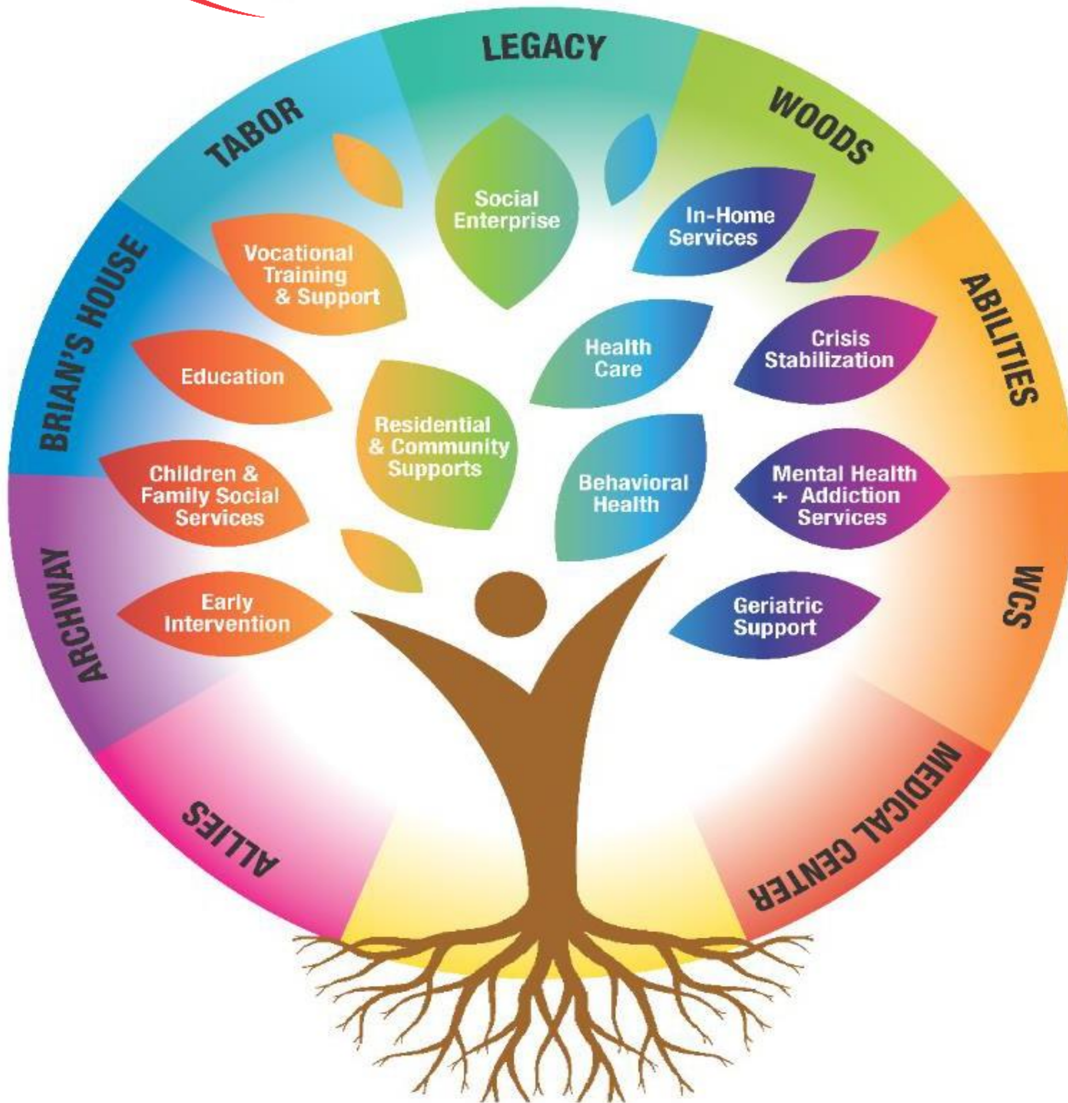
Woods System of Care

Objectives for Today

Participants will learn about:

1. The need for disability inclusive and integrated health services for people with intellectual disabilities, autism, and mental health challenges
2. Common barriers to accessing care and health disparities
3. Integrated care models and partnerships
4. Policy implications

Who we are and why this topic is so important to us



Woods Services is a population health management organization that through its network of providers in PA and NJ provides life cycle care to meet the lifelong needs of children, adolescents, and adults with intellectual disabilities and autism (ID/A), acquired brain injuries and /or mental health challenges who may also have complex medical and genetic conditions.

- Locations in Pennsylvania and New Jersey through Woods and ten affiliates
- Serving **32,000+** children, adolescents, and adults
- Referrals from **175** school districts and **23** states
- **6,600** employees in the Woods System of Care

System of Care Partners

The Population Woods System of Care Serves

- Children and adults with intellectual disability/autism and acquired traumatic brain injury with co-occurring psychiatric conditions
- Complex medical, psychiatric and behavioral challenges
- Co-occurring conditions needing involvement of many specialists
- Complex neurological and genetic conditions often requiring the need for ancillary therapies (OT, PT, Speech)
- Children and adults with behavioral health challenges

Prevalence of Intellectual Disability and Autism

- 7 million people in the U.S. have intellectual disability
- 1 in 36 children are diagnosed with Autism (continues to increase, as compared to 1 in 44 children in 2021, and 1 in 150 in 2000)
- 2.7% of the children in US are diagnosed with ASD
- Ratio boys to girls is 4:1

* https://onlinelibrary.wiley.com/doi/pdfdirect/10.1002/aur.2696

Complex Health Needs: Interplay Between Physical and Mental Health

- 40% of individuals with intellectual disability or autism have a co-occurring mental health condition
- 45% of Medicaid beneficiaries with intellectual disability or autism have additional co-occurring chronic conditions
- Similar to aging population, this population is at risk for poly-pharmacy which carries its own risks
- Individuals on psychotropic medications require monitoring for negative impact on physical health
- This population tends to be high utilizers of the ER and inpatient hospitalizations, often for preventable conditions

Disparities in Access and Health Outcomes

People with intellectual and developmental disabilities and autism experience significant barriers to care and thus health disparities.

BARRIERS TO ACCESS

- Many providers do not take Medicaid because reimbursement rates are low.
- Provider visits often require more time for this population, which means providers cannot afford to serve them due to the low reimbursement rates.
- Providers may not be trained to address communication and/or behavioral challenges (lack of training) – or they may discriminate
- Office and exam rooms may not have adequate physical layout to accommodate physical handicaps.

HEALTH DISPARITIES

- Shorter life expectancy
- Higher rates of co-occurring conditions, sensory impairment
- Higher rates of epilepsy, gastrointestinal and psychiatric disorders
- Higher rates of undiagnosed or poorly managed chronic diseases
- High rates of ER utilization, especially for psychiatric reasons, among people with autism spectrum disorder
- Lower rates of immunizations

*Anderson, L. L., Humphries, K., McDermott, S., Marks, B., Sisirak, J., & Larson, S. (2013). The state of the science of health and wellness for adults with intellectual and developmental disabilities. *Intellectual and developmental disabilities*, *51*(5), 385-398.
** Krahn, G. L., & Fox, M. H. (2014). Health disparities of adults with intellectual disabilities: what do we know? What do we do?. *Journal of Applied Research in Intellectual Disabilities*, *27*(5), 431-446.

Cost of Care

As a result of this inequitable, fragmented system, people with intellectual and developmental disabilities experience elevated costs.

- Adults with both intellectual or developmental disability and autism spectrum disorder spend **five times more annually on healthcare than the general population**. *
- Over the course of a lifespan, the cost of care is $2.4 million for individuals with co-occurring intellectual disability and autism, compared with $1.4 million for individuals with only autism, and $188,000 for the general population. *
- For people with intellectual disability *and* complex co-occurring medical and psychiatric needs, such as the population that Woods serves, the **lifetime cost of care is closer to $6 million**, conservatively assuming a life expectancy of 60 years.**

* Oss, M. E. (2023, January 5). The integration driver for ASD and I/DD. Open Minds. https://openminds.com/market-intelligence/executive-briefings/the-integration-driver-for-ASD-i-dd/

** Based on internal agency data.

Push Toward Health Equity and Policy Change

- Support the Healthcare Extension and Accessibility for Developmentally Disabled and Underserved Population Act
- Build, train, educate, and fairly support a healthcare workforce that ensures fair, just, and culturally appropriate care for people who have ID/A
- Improve systems for collecting uniform demographic, prevalence and healthcare data
- Pilot ID/A equity-focused value-based care demonstration projects in community-based healthcare settings
- Establish regulatory policies and equity standards that strengthen inclusive, friendly, safe, and healthy ID/A environments
- Strengthen public health infrastructure at the community level to support complex care of people with ID/A

Exceptional Workforce Challenges

A global crisis:

- Healthcare workforce – people leaving the profession (in 2022 145,000 people left the workforce in the U.S. alone)*
- Direct care workforce – shrinking adult working age population vs. increase in aging population

Impact of these problems

- Long wait times for services, especially behavioral health/psychiatric services
- Service providers have long waiting lists
- All of this results in poor health outcomes

*Oss, M.E. (2022, October 25). *Open Minds*. "*The Clinical Talent Gap.*" *https://openminds.com/market-intelligence/executive-briefings/the-clinical-talent-gap/*

Solutions: Models for Conceptualizing Disability

- Medical/biomedical model – primarily a medical condition; can be prevented or managed to optimize functioning
- Social model (1970s) – failure of policy, cultural and physical environments
- Biospychosocial model – recognizes psychological, social and behavioral dimensions of a medical condition.* ***This is the foundation for an integrated care model that addresses all life domains.***

*https://www.frontiersin.org/articles/10.3389/fpubh.2022.977453/full?ref=disability-debrief

Integrated Practice Assessment Tool (IPAT)

COORDINATED KEY ELEMENT: COMMUNICATION		CO-LOCATED KEY ELEMENT: PHYSICAL PROXIMITY		INTEGRATED KEY ELEMENT: PRACTICE CHANGE	
LEVEL 1 Minimal Collaboration	LEVEL 2 Basic Collaboration at a Distance	LEVEL 3 Basic Collaboration Onsite	LEVEL 4 Close Collaboration Onsite with Some Systems Integration	LEVEL 5 Close Collaboration Approaching an Integrated Practice	LEVEL 6 Full Collaboration in a Transformed / Merged Integrated Practice

* Developed by Bern Heath, Pam Wise Romero, and Kathy Reynolds

Woods System of Care

What Does Disability-Specific Healthcare Look Like at Woods?

- Continuum of Care to accommodate changing needs of clients over the lifespan
- Integrated care model which takes into consideration the whole person
- Healthcare providers who are well-versed (trained and experienced) in treating complex populations
- Environmental considerations – accessible and sensory-friendly waiting areas and exam rooms
- Thoughtful appointment scheduling
- Data-driven population health approach; share what we are learning
- A seat at the table to influence Health Care Policy – continued advocacy

Integrated Health Services

Social Determinants of Health

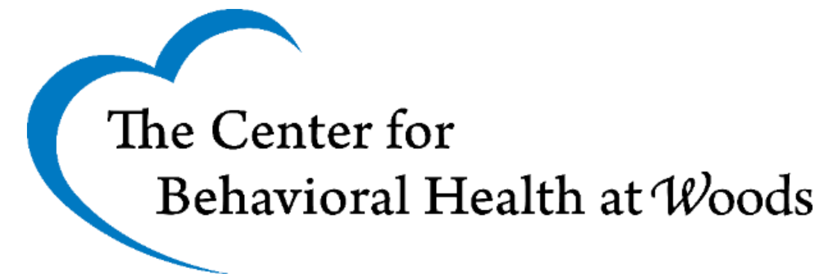
Same concept, different buckets

Woods Model

Patient-Centered Care Model

- Services delivered through a network of affiliates
- Geographic concentration allows for better care coordination, intensity of services along a continuum that people can access episodically and throughout the lifespan
- *Tailoring services to meet the unique needs of each individual to create* ***a full life cycle of care management***

Enhancements to the System of Care -- Integrated Health Services



The Medical Center at Woods – Foundation for Integrated Care Model and New Program Development Across the System of Care

- Patient-Centered Medical Home
- Integrated Care (Primary Care, Psychiatry, Specialty Care, Dental)
- Extensive partnerships which enhance services AND train next generation of providers
- Care coordination across specialties, health systems, and transitions between levels of care

Integrated Care Model

- Partnerships – pharmacy, multiple hospitals, health systems, and medical schools
- Extend and enhance care
- Training next generation of providers

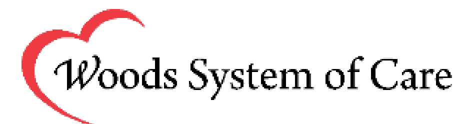
Health System, Pharmacy, Managed Care/Insurer and Academic Partnerships – PA and NJ

School of Medicine
TEMPLE UNIVERSITY®

Penn Dental Medicine
UNIVERSITY of PENNSYLVANIA

DREXEL UNIVERSITY College of Medicine

Salem Medical Center



Meeting People Where They Are

- Growing trend to deliver healthcare in new ways, accommodating different levels of care, and understanding that treatment such as short-term and outpatient residential settings are short term, with the goal of transitioning people as quickly as possible back to the community:
  - ✓ Community-based/outpatient vs. hospital settings
  - ✓ Home-based care
  - ✓ "Hospital-at-Home" models
  - ✓ Crisis stabilization and prevention (inpatient, mobile crisis teams, telehealth)
  - ✓ Telehealth

Integrated Treatment Approach

- Data-driven medication management
- Minimize medications where possible
- Minimize polypharmacy
- Coordinate with primary care, especially monitoring psychotropic medication impact on physical health
- Rule out medical etiology contributing to worsening in behavior prior to starting psychotropic medication.

Integrated Treatment Approach– How It Works Case Example

G.S. is a 17 year old female ASD, ID and disruptive mood dysregulation disorder presented with intense mood irritability, aggressive outbursts and elopement behaviors needing multiple restrictive procedures. These behaviors were more intense in school than at the residence. Psych was consulted.

Process:

1. Careful review of the medical records
2. Obtain behavioral data and incident reports from both settings
3. Discussion with mom

Recommendations:

1. Complete functional behavioral assessment both at school and at home to identify triggers, and antecedents to behavior.
2. Once the function of the behavior is identified develop interventions to address the behavior.
3. Actively engage and train the staff working with G.S. in the process to consistently implement interventions.
4. Correlated the data with menstrual cycles. There appears to be a pattern of worsening prior to the start of her menstrual period. Referral to PCP to consider OCP.
5. Review of the psychotropic medications to simplify the regime.

Integrated Care Model Summary

Key Characteristics:

- High degree of collaboration and communication among primary care/specialists/psychiatry/ behavioral health/residential and nursing teams.
- Sharing of information related to patient care and development of a comprehensive treatment plan to address the biological, psychological and social determinants of health for each individual we serve.
- Collaboration with outside agencies to break the barriers and fill in the gaps of service to provide a continuum of care.
- Implementation of the integrated electronic health record is in the process.

Benefits:

- Enhanced access to services
- Improves the quality of care
- Lowers overall healthcare costs by reducing unnecessary tests and trips to the emergency room

Summary: Strategies for Change

- Train – and support -- the next generation of providers (all types of health professions)
- Technical assistance for health systems and hospitals to be more "disability friendly"
- Advocate for better data collection systems for all aspects of health and disability
- Advocate for policy changes to improve payment systems, create incentives for providers to serve people with disabilities more effectively, incentivize new models of healthcare delivery that reach more people where they need services
- Partnerships, partnerships, partnerships

Q & A

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