Mapping the Road to Recovery: Addressing the Cognitive Challenges
Susan Robinson, MA/CCC-SLP, MBA

ASHA Disclosure Statement
I have the following relevant relationships with the products or services described, reviewed, evaluated, or compared in this presentation:

Financial:
 MossRehab – employee

Non-financial:
 None
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Objectives

- Describe state funding opportunities for vocational goals and the waiver programs: HIP, COMMCARE, Independence, OVR, and the changes over the years
- Discuss the implications of TBI as a life-long condition
- Identify important factors for service utilization to maximize use of benefits

Role of Advocacy

- Advocacy for TBI started in 1980 leading to the development of the National Head Injury Foundation → BIAA, JHTR
- Public policies → National Database on TBI, Brain Injury Awareness Month
- 5.3 million people had permanent disability due to a TBI (1999) → need for increased service to address acute and long-term consequences of BI → states needed to develop TBI Advisory Board, a lead state agency, a needs assessment and an action plan
- Federal recognition of TBI as a source of disability → TBI Act of 1996, Rehabilitation Act
- BUT lack of funding for community-based services and long-term services to support independent living

Life-Long Challenges

• Oklahoma City bombing - 10 years later:
  – Majority of survivors reported receiving outstanding trauma, acute & rehabilitative care. But 10 years later many still had needs for care and treatment for ongoing pain, emotional problems, limbs not functioning the same, and other injuries “that have never stopped infringing on their lives”
  – Support initially - still could use help
  – TBI??: only 5 of the 20 received info about sustaining a TBI but most continue to have symptoms 10 years later
  – Effects of PTSD
  – Return to work: yes but not the same, no, “they are not going to win”
  – Physical & psychological trauma & the TBI, resulting in years of pain and problems, requiring medical as well as psychological treatment


Life-Long Challenges

• Canadian study (2011):
  – Lack of Resources and infrastructure
  – Minimal coordination of services
  – Inappropriate Waiting Environments: nowhere to go after acute inpatient, specifically that understand or can deal with ABI
  – Need for individualized treatment
  – Availability varies across regions
  – Delayed diagnosis or misdiagnosis of ABI: to differentiate between symptoms of mental illness and symptoms of brain injury

Life-Long Challenges

- Every state has different funding/waivers
- State programs differ in comprehensiveness and integration
- States’ Medicaid programs use home and community-based waiver programs to reduce institutionalization but limited so unable to serve all who need

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Pennsylvania:
- Resources and infrastructure
- Availability varies across counties in PA – even within Philadelphia due to transportation issues
- Delayed diagnosis or misdiagnosis – differentiate between symptoms of mental illness and symptoms of brain injury
Role of Cognition

Ambulating .... with supervision
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Funding Across the Continuum

<table>
<thead>
<tr>
<th>Typical Funding Source</th>
<th>Acute</th>
<th>Inpatient</th>
<th>Outpatient</th>
<th>Community Re–Entry</th>
<th>Vocational</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health Insurance</td>
<td>26.74 days</td>
<td>22.97 days</td>
<td>2–3 months</td>
<td>12 months (under HIP)</td>
<td>2–3 months</td>
</tr>
<tr>
<td>Health Insurance</td>
<td>19.73 days (regional)</td>
<td>21.47 days (regional)</td>
<td>12.63 visits</td>
<td></td>
<td></td>
</tr>
<tr>
<td>HIP COMMCARE</td>
<td>21.66 days (national)</td>
<td>20.2 days (national)</td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>

Source for acute and inpatient: e-RehabData

Head Injury Program (HIP)

- Goal: to help individuals with a TBI live independently in their homes and communities
- Managed under the PA Department of Health
- Services available:
  - Residential facility
  - Day treatment facility/Outpatient
  - Other home or community based settings
- Pre–enrollment assistance provided by BIA–PA: 1–866–635–7097

http://www.portal.state.pa.us/portal/server.pt/community/head_injury_program/14185
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HIP Eligibility

- Eligibility requirements:
  - US citizen
  - 21 years of age or older
  - TBI after July 2, 1985
  - PA resident at time of injury and application
  - All applicable financial resources used
  - Personal (not family) income below 300% of Federal Poverty Income Guidelines

http://www.portal.state.pa.us/portal/server.pt/community/head_injury_program/14185

Pennsylvania Waivers

<table>
<thead>
<tr>
<th></th>
<th>COMMCARE</th>
<th>Independence</th>
<th>OBRA</th>
</tr>
</thead>
<tbody>
<tr>
<td>Eligibility</td>
<td>PA residents 21 and older with TBI and require a Special Rehabilitative Facility (SRF) level of care</td>
<td>PA residents 18 –60 with a severe physical disability requiring a nursing facility level of care</td>
<td>PA residents 18 and older with a severe developmental disability requiring ICR/ORC level of care</td>
</tr>
<tr>
<td>Functional limitations</td>
<td>in 3 or more life activities: mobility, behavior, communication, self-care, self-direction, capacity for independent living, and cognitive capacity (judgment, memory, reasoning)</td>
<td>In 3 or more life activities: mobility, communication, self-care, self-directions, capacity for independent living, and learning</td>
<td>in 3 or more life activities: mobility, communication, self-care, self-directions, capacity for independent living, and learning</td>
</tr>
</tbody>
</table>
COMMERCIAL Waiver

- Home and Community-Based Services Waiver for Individuals with TBI
- Goal:
  - to help person remain as independent as possible
  - to prevent inappropriate and unnecessary institutionalization by providing home and community-based services as a cost-effective alternative to institutional care.
  - Live in the most integrated community setting appropriate to their individual service requirements and needs

OVR

- Goal: prepare for, obtain, or maintain employment
- Provides services that enable individuals with disabilities to find jobs or keep their existing jobs
- Any physical or mental impairment that is a substantial impediment to employment may qualify an individual for vocational rehabilitation services
OVR

- An Individualized Plan for Employment (IPE) is developed with the consumer, outlining vocational objectives, services, providers, and responsibilities.
- Financial eligibility determined by OVR

OVR

- **Diagnostic Services**: Medical, psychological, and audiological examinations
- **Vocational Evaluation**: Aptitude, interest, general ability, academic exams, work tolerance, and "hands-on" job experience to understand vocational potential
- **Counseling**: Vocational counseling to better understand potential, abilities, set realistic vocational goals, develop successful work habits
- **Training**: Education to prepare for a job
- **Education**: School funding assistance usually if in demand field
- **Restoration Services**: Medical services and equipment such as PT or OT, wheelchairs, automobile hand controls to enable pursuit of employment
- **Placement Assistance**
- **Assistive Technology**
- **Support Services**: Home modifications, Job site modifications, text telephone, hearing aids

www.portal.state.pa.us
Changes in State Funding

- HIP – wait lists
- COMMERCARE
- OVR
- MLTSS → CHC (Community Health Choices)

CMS: HCBS Final Rule

- States may use federal Medicaid funds to pay for home and community-based services (HCBS)
  - supports enhanced quality in HCBS programs
  - adds protections for individuals receiving services
  - ensures full access to the benefits of community living
  - promotes receiving services in the most integrated setting
HCBS Final Rule Highlights

- Regulations enacted under the Affordable Care Act offer expanded HCBS and target services to specific populations.
- Defines and describes the requirements for home and community-based settings.
- Defines person-centered planning requirements.
- Provides states with the option to combine coverage for multiple target populations into one waiver that focuses on functional needs.

Long-Term Supports and Services (LTSS)

- Expanding community options
  - Not rapidly enough to keep up with growing demand.
- Pennsylvania has made progress on reforming its LTSS system.
- Increased LTSS funding from 37.3 percent in 2011 to 41.9 percent in 2013
  - Pennsylvania lagged significantly behind the national average, ranking it 37th among states.
MLTSS in Pennsylvania → Community Health Choices (CHC)

Under Governor Wolf’s leadership, the Pennsylvania Departments of Human Services (DHS) and Aging (PDA) are developing a new program for older Pennsylvanians and adults with physical disabilities called Community Health Choices (CHC)

- Committed to creating a system that allows Pennsylvanians to:
  - receive services in the community
  - preserve consumer choice
  - allow consumers to have an active voice in the services they receive

- Roll out in three phases over three years, beginning in January 2017

MLTSS in Pennsylvania → CHC

Community HealthChoices:

- Serve more Pennsylvanians who need long-term services and supports in the community
- Build on the values and processes of the HealthChoices program
MLTSS in Pennsylvania → CHC

Six waiver programs to be combined in CHC:
- Aging
- Attendant Care
- AIDS
- CommCare
- Independence
- OBRA

Currently, these waiver programs are managed by the DHS Office of Long-Term Living (OLTL).

CHC MCOs

- Coordinate health and long-term services and supports (LTSS) through managed care organizations (CHC-MCOs)
- Participants will have a choice of two – five CHC-MCOs in each region
- Includes value-based incentives to increase the use of home and community-based services (HCBS)
- Use standardized outcome measures to assess overall program performance and improve the CHC program over time
CHC MCOs

- Serve an estimated 450,000 individuals
  - 130,000 older persons and adults with physical disabilities who currently receive LTSS in the community and in nursing facilities
- Accountable for most Medicaid-covered services
  - preventive services
  - primary and acute care
  - LTSS (home and community-based services and nursing facilities)
  - prescription drugs
  - dental services
- Dual eligible participants (i.e. those who have Medicaid and Medicare coverage) will have the option to have their Medicaid and Medicare services coordinated by the same MCO

When to refer??

- HIP
- Waivers
- OVR
Placement in the continuum

- Dependent on severity, resources
- Ideal trajectory: acute → inpatient → outpatient → home/community → vocational
- What if no inpatient?
- What if no/limited outpatient, e.g. if all cognitive?
- What if no home/community?

Outcomes

- Patient and clinician preference for home-based therapy; however, no statistically significant difference in outcomes compared to clinic-based
- Outpatient therapy program equally effective when performed at home vs outpatient hospital setting in terms of goal achievement, psychosocial reintegration, ability and adjustment and effect on environmental barriers
- Trend towards a greater improvement in goals following the home-based treatment phase

Doig, Goal-directed outpatient rehabilitation following TBI: A pilot study of program effectiveness and comparison of outcomes in home and day hospital settings, Brain Injury, October 2011; 25(11): 1114-1125
Pennsylvania study: using MPAI (Mayo–Portland Adaptability Index) data obtained through the Outcome Info system for a group of providers in Pennsylvania (Pennsylvania Association of Rehabilitation Facilities):

- Early intervention results in better outcomes
- Progress can still be seen even when initial injury or illness was years ago when participating in an intensive program
- Supported living programs accomplish their stated goal of stabilizing functional status for participants


Mayo–Portland Adaptability Index:
- Abilities
- Adjustment
- Participation

Designed specifically for individuals with ABI
- Covers physical, cognitive, emotional, behavioral and social issues
- 3 different normative data for scoring: staff, person with ABI, significant other
- Widely used in PA and by TBI Model Systems of Care
Brain injury can be a life-long disability needing various types of ongoing support along the way.

A patient-centered collaborative approach needs to:
- emphasize family education to maximize the survivor’s abilities and roles in a community setting
- needs to change as the person changes
- needs to acknowledge the long-term effects of the injury

Life changes can affect a person with a TBI differently.

**Role of Advocacy**

Increased advocacy can lead to increased support/services for people with TBI.
Thank You

References

References


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http://www.medicaid.gov/Medicaid–CHIP–Program–
Information/By–Topics/Long–Term–Services–and–
Supports/Home–and–Community–Based–Services/Home–and–Community–Based–Services.html