Learning Objectives

- Be able to give an example of how a care manager might be involved in coordinating care for a patient with TBI.
- Be able to discuss the importance of TBI prevention and control.
- Be able to describe the benefits of support groups for persons with brain injury and their families or caregivers.
- Be able to explain the function of a special needs trust for a person with TBI.
- Be familiar with the sweeping provisions of the Affordable Care Act.
- Be able to summarize the meaning of the Olmstead decision in light of persons with brain injury.
- Be able to articulate the significance of The Rehabilitation Act of 1973.
- Be able to describe the benefits of support groups for persons with brain injury and their families or caregivers.

Case Management Topics

- CARE MANAGEMENT
- LIFE CARE PLANNING
- ADVOCACY & PUBLIC POLICY
- SUPPORT GROUPS

Case Management

- A method to manage unique and high risk conditions
- Needed by individuals whose self-care capacity is diminished
- Collaborative process of assessment, planning, facilitating, care coordination, evaluation and advocacy
- Practice across all health care settings
Domain 1: Processes and Services
- Case management should occur within a systematic process which allows for the navigation of the patient and family through the continuum of care
- Encompasses the process on the right

Domain 2: Resource Utilization and Management
- Case managers must develop strategies to oversee and protect the limited health care dollars available
- They must continually evaluate medical necessity of planned health care procedures
- They must continually evaluate their appropriateness and efficiency, in order to ensure that services obtained will be covered by the health plan benefits of the patient

Domain 2: Psychosocial and Economic Support
- This involves:
  - Education of the patient and family regarding services
  - Facilitating access to services and funding sources
  - Identifying resources and supports
  - Assessing social support systems and caregiver burden
  - Ensuring that caregivers are capable as well as available

Domain 4: Rehabilitation
- This domain focuses on areas pertinent to overall rehabilitation, with a clear emphasis on vocational aspects of rehabilitation
- The domain items target areas like:
  - Environmental modification to address accessibility barriers
  - Identification of specialized services like work hardening
  - Facilitation of return-to-work with an understanding toward what accommodations or modifications may be necessary
Domain 5: Outcomes

- The main focus of this domain is on the outcomes, including:
  - Collection
  - Analysis
  - Reporting

  This includes assessing both the quality and effectiveness of outcomes in a variety of areas including:
  - Clinical
  - Financial
  - Quality of life

Domain 6: Legal and Ethical Practices

- Within the legal and ethical domain, case managers have a duty to adhere to:
  - Pertinent regulatory requirements (e.g., ADA),
  - Accrediting standards (personal licensure or certification),
  - Legal requirements (state, federal, and local laws),
  - Ethical standards, and
  - Confidentiality and the protection of patient information (e.g., HIPAA)

Case Management & Advocacy

- Responsible for both educating and listening to patients
- Care coordination
- Communicating among team members
- Resolving disagreements
- Brokering of services
- Obtaining consent
- Appealing denials
- Establishing relationships

Life Care Planning

When is a Life Care Plan needed?

- A catastrophic injury often leaves an unexpected need for a thorough and comprehensive plan to address medical, rehabilitative, and other present and future concerns

- A Life Care Plan (LCP) is often required in these circumstances

Elements of a Life Care Plan

- The plan must utilize evidence-based standards of care and recognize clinical practice guidelines
- It should systematically identify all the intricate details involved in dealing with a catastrophic injury from the day of the evaluation to the end of the individual’s expected lifespan
- Plan should provide a blueprint for the families of persons with injuries to assist in their management and care

Life Care Planning

Key criteria essential to a Life Care Plan (LCP) include:

- Must be specific to the individual
- Must reflect full understanding of injuries and resultant disabilities
- Must consider possible complications or co-morbidities
- Must look at both short and long term needs
Life Care Planning

LCPs have utility across a variety of different applications, including tools for:
- Personal injury, product liability, and medical malpractice cases,
- Families to use as a roadmap to identify services,
- Management of special needs trusts,
- The insurance industry for cost containment,
- The elder care industry for identification of long term care needs,
- Veterans with Polytrauma, and
- Case managers to maximize patient recovery and identify needed services for patients with catastrophic injury.

Special Needs Trusts (SNTs)

- Different types of Special Needs Trusts
  - First Party SNT aka Medicaid Payback Trust
  - Third Party SNT
  - Inter Vivos (during life) SNT
  - Pooled Trust/Community Trust
  - Start process with an attorney and determine a trustee

Life Care Plan Checklist

- Projected Evaluations
- Projected Therapeutic Modalities
- Diagnostic Testing/Education Assessment
- Wheelchair Needs
- Wheelchair Accessories and Maintenance
- Aids for Independent Functioning
- Orthotic/Prosthetics
- Home Furnishings and Accessories
- Drugs/Supplies
- Home Care/Facility Care
- Future Medical Care-Routine
- Transportation
- Health and Strength Maintenance
- Architectural Renovations
- Future Medical Care/Surgical
- Intervention or Aggressive Treatment
- Orthopedic Equipment Needs
- Vocational and Educational Plan
- Potential Complications

Advocacy & Public Policy

Advocacy
- Person/organization that speaks/writes in support or defense of an individual or cause
- Can be family, friends, case managers, attorneys/guardians
- A self-advocate is an individual who exercises personal choice and free will for themselves

Public Policy
- Combination of enacted legislation, regulations and judicial interpretations of federal, state and local laws
- Advocates work to improve access to healthcare, education, housing, transportation, employment and income

Public Policy

- Known as CHIP
- Covers uninsured children in families with incomes that are too high to qualify for Medicaid
- Each state has flexibility in designing program
- Supplemental Security Income (SSI) - prior work experience not necessary; low income and minimal assets
- Social Security Disability Insurance (SSDI) - need sufficient prior work experience
Having a disability does not automatically address the intervention, special education, or related services to be provided, and how often, as well as any required accommodations.

Known as IDEA
- Addresses the intervention, special education, and related services provided by states and public agencies which accept federal funding for children with disabilities in 14 specified categories, including TBI.
- Mandates that interventions be provided, and how often, as well as any required accommodations.

Known as IEP
- Key requirement of IDEA is that schools must develop an Individualized Education Program.
- Describes the student's present academic performance and what the student's disabilities affect that performance.
- Specifies the special education and related services to be provided, and how often, as well as any required accommodations.

Known as ADA
- Prohibits discrimination in employment, state and local government.
- Mandates public accommodations in commercial facilities, transportation and telecommunications.
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- Prohibits discrimination in health insurance.

Known as OBRA
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Known as ACA or “Obama-Care”
- Patient Protection and Affordable Care Act (PPACA) signed into law in March 2010.
- A mandate on individuals and employers to obtain or provide health insurance by 2014 or face penalties, except in the case of financial hardship and religious objections.
- Establishment of state-based Health Benefit Exchanges (also known as State Insurance Exchanges) effective in 2014 with an essential benefits package.

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### Public Policy

- **The Traumatic Brain Injury Act of 1990**
  - Only federal legislation that specifically addresses TBI
  - The act authorized the National Institutes of Health to focus on these 3 areas:
  - **Research:** National Institute of Neurological Disorders and Stroke (NINDS) to make grants for basic research.
  - **Prevention:** Authorize the Center for Disease Control and Prevention (CDC) to study where and how people get injured and what happens to them afterward.
  - **Improved Services:** U.S. Department of Health and Human Services to make grants to state government agencies and Protection and Advocacy organizations to improve access to services for people with brain injury.
  - Many of the federal laws support federal programs and joint federal-state programs which pay for services for persons with brain injury.
  - Some states have enacted trust fund legislation for the same purpose.

### The Need for Support Groups

- **Starting in the 1970s,** and steadily thereafter, mortality rates due to traumatic brain injury in the United States improved considerably.
- Two major contributions were vehicle-related safety improvements and improvements in trauma care.
- Collectively, these medical and societal enhancements resulted in mortality rates due to TBI dropping 20% from 1980 to 1994.
- As a result, fewer people were dying, and more people were surviving and living with brain injuries.

### Support Groups

- Provide a forum to discuss difficulties/achievements with a group of others who have common issues.
- Gain knowledge on how to navigate the health system, access insurance or public benefits.
- Social and psychological support for caregivers.

### Support Group Types

- A broad definition of a support group is “a gathering of people who share a common health interest or concern.”
- Support groups developed for caregivers, often family members of those injured, as well as for those who themselves were injured.
- For each of these groups, the support group served unique functions and purposes.
Support Groups: Caregivers

- Families members are essential to their loved one’s recovery.
- They are often primary caregivers as well.
- Being a caregiver can leave individuals vulnerable to illness and distress.
- Support groups can be beneficial.

Impact on Family & Caregivers

Impairments of the person with the injury impact caregiver distress

Social Impairments
- Which directly impacted psychological distress in family caregivers

Cognitive Impairments
- Which directly impacted psychological distress in family caregivers

Behavioral Impairments
- Which indirectly impacted psychological distress via:
  - Impact on family functioning and participation impairments
  - Work and independent living skills

Support Groups: Caregivers

- Research has suggested that family caregivers can:
  - Adversely impact psychological outcomes for their loved ones.
  - One area of interest was the finding of a strong relationship between the caregiver’s level of perceived social support and their loved one’s psychological outcomes.
  - Lower levels of caregiver perceived social support related to higher levels of distress and lower levels of life satisfaction in the loved one.
  - Conversely, higher levels of caregiver perceived social support related to lower levels of distress and higher levels of life satisfaction in their loved one.

Support Groups: Caregivers

Family issues after injury

- Feeling confused and in denial about neurobehavioral sequelae
- Having strong mixed feelings about the person with the injury
- Feeling uncomfortable or trapped living with a stranger
- Feeling unprepared and unprepared not socializing after the survivor is located
- Disappointment in rehabilitation effectiveness
- Failure to recognize the impact of injury on the entire family
- Feelings of guilt have a detrimental impact
  - Loss of relationships, feeling isolated and alone
  - Neglecting oneself
  - Feeling stressed and overwhelmed
  - Having difficulty remaining patient
  - Managing problems effectively
  - Blaming other people for causing or exacerbating problems
  - Worrying and focusing on the negative

Support Groups: Caregivers

- Feeling frustrated and confused when presented with contradictions and demands
- Lack of important information
- Not being comfortable in successful asking for help
- Avoiding direct and honest communications
- Feeling uncomfortable talking to others about the injury
- Feeling uncomfortable asking questions

Support Groups: Individuals Living with a Brain Injury

- Support group benefits for caregivers include:
  - Reduction of the pressures and burdens of caregiving
  - Reductions in anger responses and stressful symptoms
  - Increased social support and satisfaction

- In a study of caregivers of individuals with dementia, factors of the support group correlating to more positive outcomes included:
  - Use of a theoretical model by group facilitators
  - Longer length of the sessions (e.g., 6 or more weekly or a total of 16 or more hours)
  - Group size of 6-10 caregivers
  - Use of a group manual, providing greater opportunity to review information
  - Use of interdisciplinary facilitators versus one discipline
  - Higher ratios of females in the group
  - Moderate severity of dementia of the caregiver’s loved one (severe or high)

Rainbow Rehab Centers
10/27/2016
**Support Groups: Individuals Living with a Brain Injury**

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  - Reduction of the pressures and burdens of caregiving
  - Reductions in anger responses and depressive symptoms
  - Increased social support and satisfaction

**Legal Rights**

- The individual with a brain injury has the same legal rights as anyone
- A legal representative may exercise those rights if the individual with the brain injury is unable to do so

**Patient’s Bill of Rights**

<table>
<thead>
<tr>
<th>Definition</th>
<th>Examples</th>
</tr>
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<tbody>
<tr>
<td>Written guarantee of basic rights for individuals in treatment programs</td>
<td>- Treated with respect, consideration and dignity</td>
</tr>
<tr>
<td>Staff are accountable to adhere to these rights</td>
<td>- Receive and send unopened mail</td>
</tr>
<tr>
<td>Violation of rights could be grounds for a lawsuit</td>
<td>- Manage financial affairs or given an account of transactions</td>
</tr>
</tbody>
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**Seclusion and Restraint**

- Used only as a measure of last resort; less restrictive measures are unsuccessful or patient/others are in imminent danger
- Inappropriate use violates Constitutional rights
- Every U.S. citizen is guaranteed constitutional rights regardless of ability/disability
- Never allowed for shortcomings of treatment program (e.g., short-staffed, poor training or lack of treatment programming)
- Can be dangerous to patients and staff
- Monitor physical and psychological status of patient
**Medically Prescribed Restraints**
- Prescribed by a physician
- Vests - prevent falling out of bed
- Helmets - patients prone to seizures
- Lap belts or lap trays
- Can be managed by patient or removed by patient’s direction

**Accreditation Standards**
- Addresses safety and quality of care
- Done voluntarily, for state licensing or federal certification
- Joint Commission (JC) and Commission on Accreditation of Rehabilitation Facilities (CARF)
- Can vary by setting

**Competency or Capacity**
- Mental ability to understand the nature and effect of one’s decisions and acts
- Only a court may determine if an individual is legally incompetent
- If person is legally incompetent then the court may appoint a representative to make decisions

**Guardianship**
- A legally-enforceable arrangement in which the guardian has the legal right and duty to care for another (the ward)
- “Natural” guardianship dissolves when the age of adulthood is reached; even for those with a brain injury unless legal action is taken
- The ward does not lose basic rights
- Does not necessarily extinguish legal rights of ward - right to vote or to marry

**Things to Know About Guardianship**
- Who the guardian is
- Extent of power/duties of guardian
- Should be clearly reflected in the probate court paperwork
- How to reach the guardian
- Who to notify if the guardian is not performing as expected
Power of Attorney

- A document where a competent person appoints another person to act for him/her in legal and financial issues
- Can be immediate or when something happens
- Durable means it is not changed when the person becomes disabled or incompetent

Confidentiality

- Health Insurance Portability and Accountability Act (HIPAA) was enacted in 1996
- Regulations developed to protect individually identifiable health information, known as protected health information (PHI), came into effect in April 2003

Confidentiality

- Identifying health information which can be linked to a person
- Protected Health Information
  - Cannot be used or disclosed without a specific authorization other than for purposes of
    - Treatment
    - Payment or
    - Health care operations

Confidentiality

- Patient’s right to consent to care after provider fully discloses all risks and facts to make informed decision
- Patient has the right to an informed decision, whether legally competent or not

Abuse, Neglect & Exploitation

- Abuse is the willful infliction of injury, unreasonable confinement, intimidation, or punishment with resulting physical harm, pain or mental anguish
- This also includes the deprivation by an individual, including a caretaker, of goods or services that are necessary to attain or maintain physical, mental, and psychosocial wellbeing
Abuse, Neglect & Exploitation

- Neglect is usually a failure to provide for the basic needs of a dependent individual.
- Exploitation is the use of a dependent individual’s property illegally or without the consent of the individual.
- Exploitation includes the expenditure of funds.

An advocate can be an individual or organization who serves on behalf of a patient. They can be formal or informal, and can help with legal/ethical issues, or funding or services. Patients can have an advocate without reprisal.

Americans with Disabilities Act (ADA)

- Enacted in 1990 to prohibit discrimination of those with disabilities.

ADA defines disability as:
- A person who has a physical or mental impairment that substantially limits one or more major life activities (major life activities include walking, breathing, seeing, hearing, speaking, learning, and working).
- A person who has a history or record of such an impairment; or a person who is perceived by others as having such impairment.

ADA – Title I: Employment

- Prohibits discrimination in recruitment, hiring, promotions, training, pay, social activities, and other privileges of employment.
- Employer must make reasonable accommodations as long as it doesn’t constitute an undue hardship.

ADA – Title II: State & Local Government

- Covers state and local government services (e.g., city buses and public rail transit).
- Give all individuals an equal opportunity to benefit from all programs, services, and activities.
- Provide services in the most integrated setting.

ADA – Title III: Public Accommodations

- All businesses and nonprofit entities who provide service to the public.
- Must comply with basic nondiscrimination requirements that prohibit exclusion, segregation, and unequal treatment.
- Private clubs, religious organizations, and private residences are exempt.

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**ADA - Title IV: Telecommunications**

- Addresses telephone and TV access for those with hearing and speech disabilities
- Use of devices for the deaf or teletypewriters
- Closed captioning of federally-funded public service announcements

**ADA - Title V: Misc. Provisions**

- Addresses relationship of the law to other laws and jurisdictions
- Includes information on insurance providers, attorneys' fees and conditions not defined as disabilities