



**Lifespan Considerations for  
Individuals with Brain Injuries**

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# Objectives



- Identify lifespan issues which serve as barriers to the long term outcomes of community living and maintaining independence
- Determine how rehabilitation supports can best meet the needs of individuals with brain injuries as they move through life activities, including aging



# Lifetime conditions associated with brain injury



- A convergence between the disabilities acquired from brain injury and the normal aging process
- The creation of a more vulnerable population of individuals living with functional limitations and healthcare problems
- Increase in the need for assistance and specialized care over the course of time related to the increase in injury severity and survivorship



# Brain Injury: Not a “Single Disability”



- Age and Disability related factors
- Enhanced survivability with increased comorbidity
- Mental health and substance abuse
- Social network issues, isolation
- Caregiver stress
- Mobility and service access issues
- Reduced income, disability related poverty



# Barriers to Maintaining Independence

- Functional problems related to physical, cognitive, psychological and behavioral consequences of brain injury
- Emergence of additional medical problems
- Social role return and reintegration problems
- Loss of life activity focus
- Emergence of post injury behavioral health issues
- Economic problems, income loss
- Limited mobility in the community
- Social network failure
- Housing problems
- Aging and caregiver issues





**Aging with a brain injury** <sup>6</sup>

# The Concept of “Just Old” vs. Aging with a Disability



- At age 80 the average person has three disabling conditions
- Most caregivers of individuals <80 are females and exhibiting disabling conditions
- Does age hide disability acquired before age 80?
- A person with disabilities acquired earlier in life may experience a worsening of those problems caused by aging in addition to age related disabilities.
- Access to specialized services for individuals with a disability acquired earlier in life may become more difficult/less available as they age



# Aging with a Brain Injury



- A thinner “margin of health”
- Diminished social support networks
- Increased rates for depression, substance abuse and suicide
- Aging effects on involved caregivers
- Difficulty accessing conventional care resources or unavailable resources with brain injury experience or specialization

# Caregivers: A Fragile Support System for the Future



- The aging of the population living with a brain injury- 18% of care recipients are 45-65
- Increased survivability and increased disability
- Relationship of comorbid conditions to primary disability
- 75% of caregivers are female, older than the population at large, 80% not employed outside of the home
- Caregivers themselves face the problem of aging
- Household incomes below the national average (Decima, 2002)



# Healthcare Needs and Disability



- Increased vulnerability to specific disease processes causes premature entry of individuals with TBI into “frail elderly” group
- Potential for decreased access to health maintenance and wellness programs
- Early onset of chronic health conditions associated with impairment which occurred earlier in life
- Increased likelihood for a person with a disability who acquires a new health condition to experience secondary functional loss
- Likelihood of more complicated/prolonged treatment for health problems
- Greater requirements for DME and assistive devices with poorer levels of adjustment to those devices (DeJong, 1997)



Does Brain Injury  
produce greater  
vulnerability to other  
health and disability  
problems?



# How can we better determine lifetime issues?



- Review of long term survivor studies
- Develop prospective studies on an ongoing basis to include cohorts who have benefited from changes in emergency care
- Consider the durability of rehabilitation outcomes over extended periods of time post injury
- Identify barriers to maintaining independence which relate to age and disability issues
- Identify factors related to producing sustainable outcomes



# Let's Review a study which involves individuals who are now 60+ years beyond their injury

- Are our assumptions about long term TBI issues correct?
- What conditions other than TBI are factors which enhance disease risk and serve to reduce functional capacity?



# Study of W.W.II Veteran's with TBI



- Followed 1776 men identified as battle casualties in 1944-45 in U.S. Navy and Marine hospitals
- 548 identified as TBI, 1228 without TBI
- Study reviewed occurrence rates for dementia, depression, stroke and post traumatic stress disorder
- Source: Plassman and Evans, 2006, 2<sup>nd</sup> Federal Traumatic Brain Injury Interagency Conference
- Plassman, BL, et al, Neurology 2000<sup>14</sup>



# Enhanced Risk of Alzheimer's Disease



- Risk of AD increases with severity of injury from Mild TBI (.75) to Severe (4.5)
- Earlier onset of dementia
- Role of genetic predisposition, presence of APOE genotype
- Role of injury severity



# Alzheimer's Disease and TBI



- APOE4 carriers twice as likely to have a poor outcome from TBI compared to non-carriers
- APOE4 carriers demonstrate a reduced likelihood of recovery of consciousness from post-traumatic coma
- Generally, we do not know APOE4 carriers at the time of TBI
- APOE4 carriers diverged from non-carriers at 6 months post-injury
- Role of APOE4 in terms of response to injury from onset and over time
- Source: Millar, Teasdale, et al, 2003



# TBI and Depression



- Life prevalence rate was 18.5% for TBI group vs 13.4% for those without TBI
- Risk of depression increases with injury severity
- Risk of depression increases as individuals with TBI age
- Pre injury depression may predispose person to post injury depression



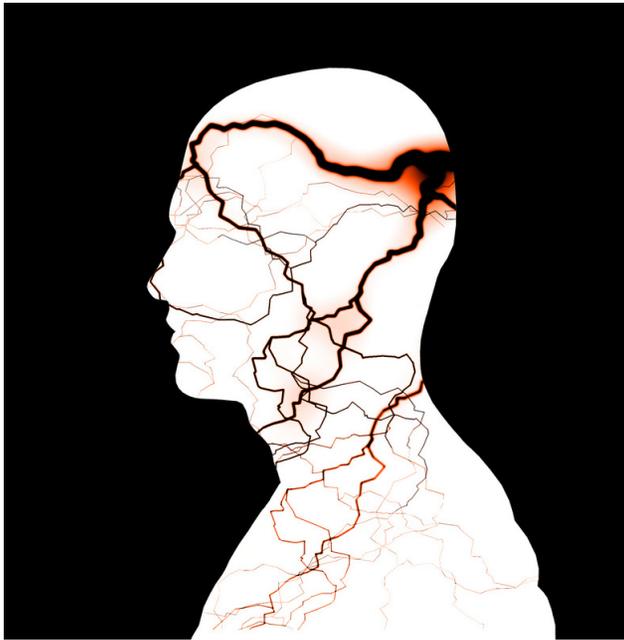
# TBI and “Stroke”



- Lifetime prevalence of “stroke” was not more common in those with a history of wartime TBI (13.4%) vs those with no history of TBI (11.2%)
- Trend toward injury severity being a factor in increased likelihood of a stroke



# TBI and PTSD



- 77% of combat veterans with PTSD report previous TBI
- 59% of those without PTSD reported a previous TBI
- Neither total brain volume loss, lesion location or post-injury cognitive change showed a relationship with PTSD



# Vietnam and Iraq and Afghanistan: Types of brain injuries and long term consequences

- Survivorship from severe TBI increased in the Iraq/Afghan war from WWII and the Vietnam era due to battlefield and field hospital interventions
- Penetrating injuries (Vietnam Head Injury Study) 53% had “No LOC” and 15% experienced prolonged unconsciousness
- Closed head injuries were more likely to produce long periods of disturbed consciousness
- Blast injuries, associated with polytrauma, 40% had TBI and 50% of those with TBI had moderate to severe brain injuries
- Multiple blast injuries outcomes were similar to those individuals with “multiple mild TBI’s” in the civilian population
- Source: Collins, Treatment of the Combat Injured, 2006

# Behavioral Health Issues in Acute Medical Care and Long Term Behavioral Issues

- Early onset of violent behavior post TBI, references to death, mangling and/or blood related to greater problems with employment, social/ sexual adjustment, somatic symptoms and emotional status
- Premorbid personality factors related to greater likelihood of long term behavioral and psychiatric problems (Collins, 2006)

Does Brain Injury predispose the individual to physical, neurologic, behavioral and psychiatric problems which will occur later in life?



The impact of  
lifelong support  
needs on caregivers



# A Young Person's Injury and a Lifetime of Disability



- Highest rate of TBI among 15-19 year olds: 550/100,000 vs 115/100,000
- Increased survivability for younger individuals
- Average life expectancy
- Lifetime costs for long term care exceeding \$4.5 million (Livneh & Antonak, 1997) exclusive of costs associated with economic (lost wages) and psychosocial supports

# Impact of TBI on Caregivers

- Behavioral, social, emotional and cognitive changes have a greater impact on caregivers than the primary disability
- Personality disorders have a significant direct effect on caregivers' mental and physical health (Andrews, 2002; Hooker, 2000)
- Cognitive impairments of older persons produces higher levels of emotional, physical and financial stress than physical care
- Wives of men with TBI experienced greater distress and emotional and physical adjustment than wives of men with SCI (Levor and Jansen, 2000)
- Duration of disease/disability is a strong predictor of mental health problems in caregivers (Trend, 2002; Thommassen, 2002; Carter, 1998)
- Most TBI survivors have a normal life expectancy (78.6 years)



# Psychological Implications for Individual and Caregivers



- Concept of “Mobile Mourning” (Haffey and Muir, 1984) effects family and primary relationships
- “Partial Death Syndrome” in response to lifestyle and functional changes (Cree, 2003; Duff, 2002; Antonak, 1993)
- Rehospitalization occurrence rate increases in years following rehabilitation for psychiatric and seizure problems
- High levels of social isolation; unemployment and limited support network
- Increased risk of violence as perpetrator or victim



# Long Term Family and Caregiver Issues



- Caregivers as “hidden victims”, reporting “mental distress” and “poor health” 46% more likely than non-caregivers
- 61% of Caregivers are women
- Competing family responsibilities
- Averaging 23 hours per week of care
- Aging and transition from home based care to community care places additional stress on caregivers
- Arranging for treatment and services
- Creating mobility and access into the community
- Housing
- Maintaining family and social relationships
- Source: Rosalynn Carter Institute, National Quality Care Coalition, University of Florida, 2006



# Caregiver Challenges

- Finding time for themselves 35%
- Managing Challenging Behaviors 31%
- Needing information/access to financial help 36%
- Needing information on activities to do 27%
- Source: Rosalynn Carter Institute, National Quality Care Coalition, University of Florida, 2006



# Family Response to Brain Injury and Long term Disability

- Coping style and satisfaction with social support network were more significant factors than injury severity in assessing positive family response
- A low number of “unmet needs” and a low number of escape/avoidance strategies were predictors of a positive family response
- Family functioning in the years post injury were an indicator of adjustment to disability for both the individual and family
- Source: Sanders, 2003 Baylor College of Medicine, Institute for Rehabilitation and Research



Does Brain Injury  
create barriers to  
family, social and  
community living  
which will increase in  
the years post-injury?





# **Outcome Issues for Children and Adolescents**

# Personality Change in Children and Adolescents Following TBI

- Personality change occurred in 13% of the cohort in the first year following TBI and 12% in the second year
- Severity was a predictor of personality change
- Pre-injury adaptive function related to changes in the second year
- Study implicate changes in dorsal prefrontal cortex and frontal lobe white matter
- Source: Max, Levin, et al, 2006



# Outcomes and Severity

- Initial loss of consciousness and GCS <8 associated with later behavioral difficulty
- 51.2% experienced persisting psychiatric disorders
- 40% experienced problems with impulsive and aggressive behaviors
- Injury severity, family history, pre injury academic functioning and psychosocial indicators related to the onset of post-injury psychiatric disorders
- Source: Max, et al, 1998, 2001



# Psychosocial Outcomes

- 93% of pediatric injuries are “mild”
- Adult pattern of initial deficit followed by recovery not seen in children (Satz, 2001)
- Injury prior to age 5 associated with greater deficits at ages 10-13 (Satz, 2001)
- Initial deficits may worsen as they interact with development and skill acquisition
- Delayed onset of deficits may be associated with injury to the prefrontal cortex
- Source: McKinlay, Dalrymple-Alford, Horwood, Fergusson, 2002; Satz, 2001



# Pediatric Characteristics: NRIO Study

- Average Age at Injury 10.7
- Average age at discharge 13.4
- Average GCS 6.8, range 3-15
- Average period post TBI was 8.5 months
- 100% MVA with 60% as Pedestrian
- 100% presented with academic and cognitive problems
- 80% with behavioral problems
- 60% with psychological/adjustment to disability problems
- Source: NRIO Outcome Validation Study, 2005



# Pediatric Outcomes: NRIO Study

- 80% participating in modified academics or vocational training with moderate (2-4 hours/day) to no to minimal supports (0-2 hours/day)
- 20% participating at pre-injury level with peer classmates
- Reduction in required supervision from family members
- Increased participation in community/school independence with moderate to minimal support levels
- 40% requiring ongoing psychological or behavioral support
- Multi year durability data indicates need for ongoing support services to maintain positive family, school, social and psychological adjustment
- Source: NRIO Outcome Validation Study, 2005



# What happens to individuals injured as children?

- Interaction between brain injury and developmental processes
- Psychosocial adjustment problems, onset of psychiatric disorders
- Family system/caregiver stress
- Lifetime consumers of specialized services
- Lifetime of disability



# Long Term Implications for Children with TBI

- High survival rate from moderate to severe injuries
- Likelihood of future psychiatric disorders, learning problems and psychosocial adjustment problems
- Early age at injury related to problems surfacing 5-8 years post injury
- Social isolation from peers caused by functional and behavioral issues
- Need for extended family supports



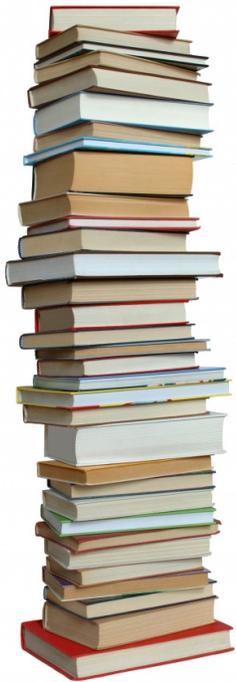
Does Brain Injury in children establish lifelong functional problems?





Increased survival rates and decreased acute medical rehabilitation stays changes potential outcomes.

# NRIO Adult Outcome Study: A Ten Year Perspective



- Average age at injury 31.9
- Decrease in time spent in acute rehabilitation over course of study (1993-2005)
- Increase in chronic medical/health problems presented at post acute admission
- Increase in the % of females over the course of the study
- Consistent % with GCS <9
- *Source: NRIO Outcome Validation Study, 1993-2005*

# 10 Year Perspective: Is Employment a Real Goal?

- Overall decrease in the % of individuals who returned to employment at discharge due to disabling conditions
- Increase in % of individuals who were unemployed, disabled or retired at the time of injury
- Increase in % of individuals employed at the two year follow-up point, indicating that the return to work may occur in the post rehab period
- Source: NRIO Outcome Validation Study, 1993-2005



# 10 Year Perspective: Independence in the Community

- In the 10 year period, average of 42.2% receive “no to minimal” paid support at the time of program discharge
- Severity factors at discharge influence support needs
- As level of independence increased over time, hours of paid support decreased and was maintained
- Individuals with greater physical disabilities report increased hours of unpaid (family) support which also decreased over time
- Independence was maintained over time
- Source: NRIO Outcome Validation Study, 1993-2005



# 10 Year Perspective: Social Role Return

- Over the 10+ year span of the study, an average of 37.3% report returning to and maintaining their primary social role without modification
- 43.1% report experiencing a change in social role status requiring support from family members
- Follow-up study observed “no regression” in social role return and noted that individuals were reassuming greater aspects of their pre injury social roles as time progressed
- Source: NRIO Outcome Validation Study, 1993-2005



# 10 Year Perspective: Emergence of Psychiatric and Substance Abuse Problems

- Psychiatric and Substance abuse problems which predated injury remained as interfering problems at the 1, 2 and 3 year intervals for individuals with moderate to moderate/severe injuries and resulting disabilities
- Psychiatric and substance abuse problems had a lower occurrence rate pre injury for the individuals with severe injuries, but remained as an interfering problem post discharge for individuals who initiated use post-injury
- Emergency psychiatric hospitalization was found to occur as a result of: relationship problems, medication non-compliance and substance abuse
- Source: NRIO Outcome Validation Study, 1993-2005



# Chronic Medical Problems Experienced by Individuals



- Seizure disorders
- Respiratory problems
- Late onset of swallowing problems
- Skin integrity
- Diabetes
- Circulatory problems
- Contractures and orthopedic problems
- Stoma care and GI complications
- Pain management and headaches
- Fatigue
- Source: NRI Outcome Study, 1993-2005; NRIO Outcome Study, 1993-2005



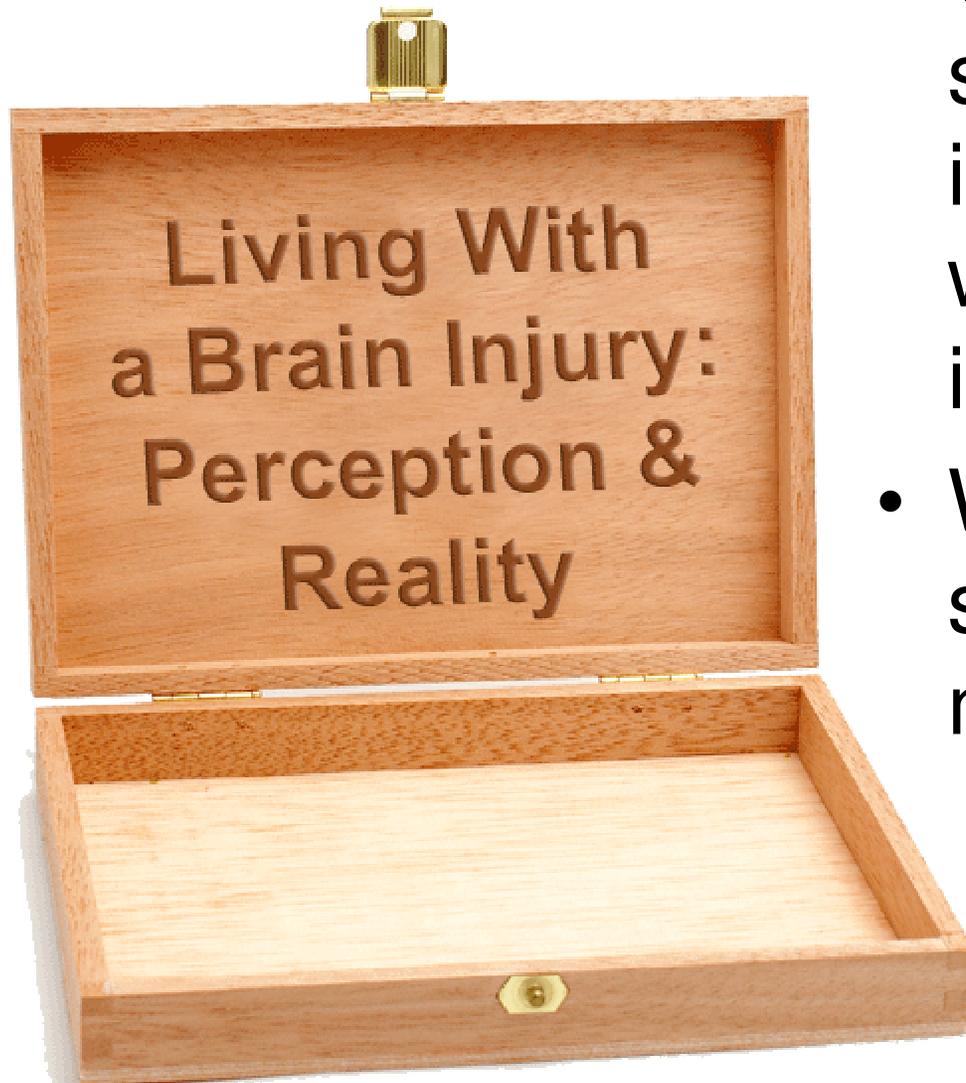
# Two 10 Year Studies, Two Countries: Same Issues



- Increased severity of injury and related conditions
- Increase in age at injury
- “Sicker and Quicker” reduced acute medical rehabilitation stays
- Reduced treatment stays in acute, post acute and community programs
- Increase in comorbidity
- Decreased financial resources available for rehabilitation
- Source: NRI Outcome Study 1993-2005, NRIO Outcome Study 1993-2005

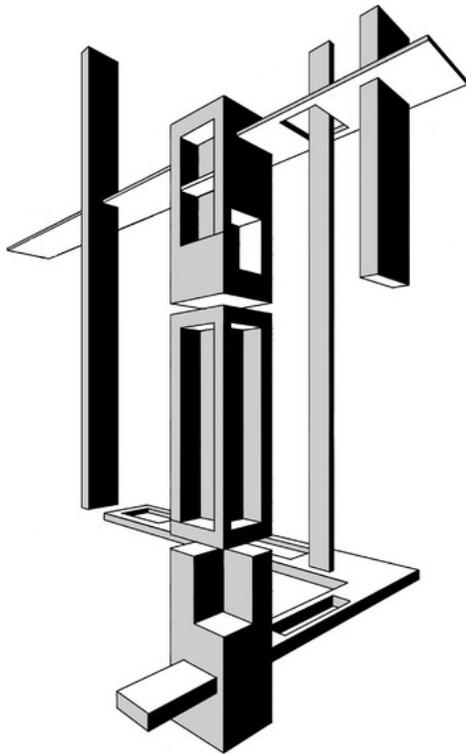
Are the changes in  
medical technology  
and rehabilitation  
effecting long term  
outcomes?





- What barriers are seen by individuals living with a brain injury?
- What barriers are seen by family members?

# Maintaining Independence: Clients' Perspective at the Ten Year Point



- Housing Choice
- Returning to live with parents or family in a dependent status
- Difficulty in accessing services outside of the home
- Difficulty in obtaining TBI support services
- Finding resources with brain injury expertise
- Economic changes
- Source: NRIO Outcome Study, 1993-2005

# Priority Issues of Family Members



- Functional physical limitations
- Chronic medical care needs
- Reliance upon others for basic care
- Transportation
- Depression
- Cognitive (memory) problems
- Behavior and Anger Management problems
- Source: NRIO Outcome Study, 1993-2005



# Caregiver Perception of Problems Associated with long term outcomes



- Decreased activity outside of the home, isolation
- Need for emergency hospitalization due to medical and psychiatric events
- High physical dependence, altered functions within family
- Accelerated aging
- Age issues of caregivers, “burnout”
- Source: NRI Outcome Study 1993-2005, NRIO Outcome Study 1993-2005



# Five and Ten Year Outcomes



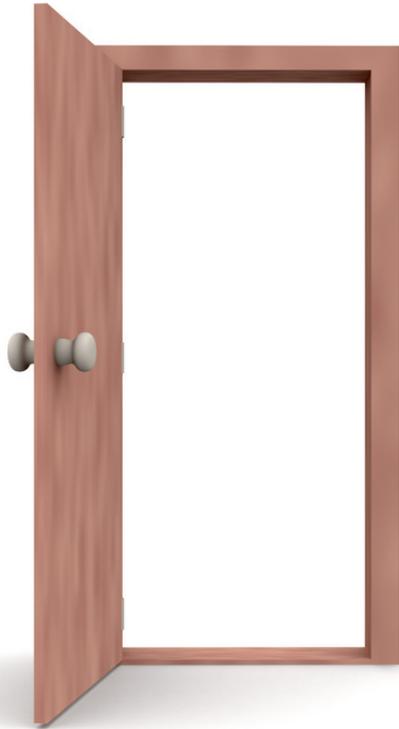
- Mid term 5-9 years
- Long term 10-35 years
- Cognitive problems: memory and “thinking”
- Vision changes
- Coordination and moving limbs
- Transportation
- Source: Kreutzer, Livingston, Taylor, West 2003

# Individuals Reporting “Unmet” Needs Ten Years Post Injury



- Needing assistance with problem solving 52%
- Increasing income 51%
- Improving job skills 45%
- Opportunities to Socialize 42%
- Increase education/training level 40%
- Manage money/budget 35%
- Improving health and “wellness” 30%
- Independence in homemaking 25%
- Legal problems 22%
- Traveling in the community 15%
- Source: Heineman, Sokol, Garvin, Bode 2002

# Lifespan Issues



- How can we meet the needs of today's brain injury survivor as they age?
- What trends are emerging in the survivor population that will impact on the future?



**Changing our perceptions and addressing the realities about lifelong rehabilitation needs**

# The Rehab Plateau: Is Change Time Limited?



- Limited understanding of plateau and the concept of ongoing improvement
- The 24 month period cited as the maximum physical recovery does not begin at the time of injury
- Long term outcome study data supports extended, possibly life time, recovery
- Outcome studies need to focus on function, adaptation and adjustment of the individual
- Source: National Institute of Health, Consensus Report on Rehabilitation of Traumatic Brain Injury, 1999

# Long Term Outcome Realities for Individuals Living with Severe Disabilities

- Increase to healthcare needs, early onset of conditions associated with “frail elderly” and enhanced vulnerability
- Increased dependency on others for care due decreased functional capacities
- High levels of caregiver stress, including “burnout”
- Increased likelihood of psychiatric and substance abuse problems requiring emergency care and treatment
- Potential for social isolation, including within family settings
- Economic problems



# Can Rehab Extend Outside of the Traditional Box?

- Consider lifetime issues in the context of service planning and delivery systems
- Development of extended rehab teams within the community and community service agencies with brain injury expertise
- Development of specific capabilities within existing systems to serve individuals with lifetime issues
- Consideration of support and activity programs to address isolation and caregiver stress



# Is extended rehabilitation the answer to lifetime issues?

- Nontraditional roles for rehabilitation professionals in the home and community
- Identifying, training and supporting “rehabilitation extenders” who work in the home and community
- Focusing on “wellness” and health improvement through participation and education
- Increasing access to services/ increasing available services across the spectrum of age
- Increasing transportation and housing options
- Consideration of economic impact of TBI and needs for greater financial resources over the course of a lifetime



# Can we change the role of the consumer with TBI?

- Increase capacity to self direct care and to case manage through education
- Increase understanding of health management needs
- Decrease crisis events
- Increase level of participation in activities within and outside of the home
- Identify situations and events which cause transitions and plan in advance
- Improve access to needed services



# The Future:

- Aging with a disability: more survivors and greater severity of disability as medical technology advances
- Home and Community Living Supports: functional and pragmatic solutions to maintain individuals in their homes
- Alternatives to institutions for the elderly and disabled: flexible supported living options, avoidance of disability ghettos
- Improved healthcare: greater options for wellness programs, access to specific expertise
- Enhanced behavioral health services for individuals with TBI: alternatives to hospitalization and hospital based supports for psychiatric and substance abuse problems
- Commitment to research focused on long term outcomes
- Prevention of injuries



# The Realities

- Enhanced survivability
- Reduced medical care and rehabilitation stays
- Increase in disability level and multiple disabilities
- Near “normal” life expectancy coupled with disabling conditions
- Needs for extended support and specialized services
- Stressed caregiver resources
- Complications associated with aging occurring earlier
- Long term health implications
- Limited community resources for extended care needs
- Economics of long term disability for the person, their family and society





Can we impact on the future?

How can we act to improve the quality of life for individuals living with a brain injury?



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