

A group of hikers with large backpacks walking on a dirt trail in a mountainous area. The image is overlaid with a semi-transparent blue filter.

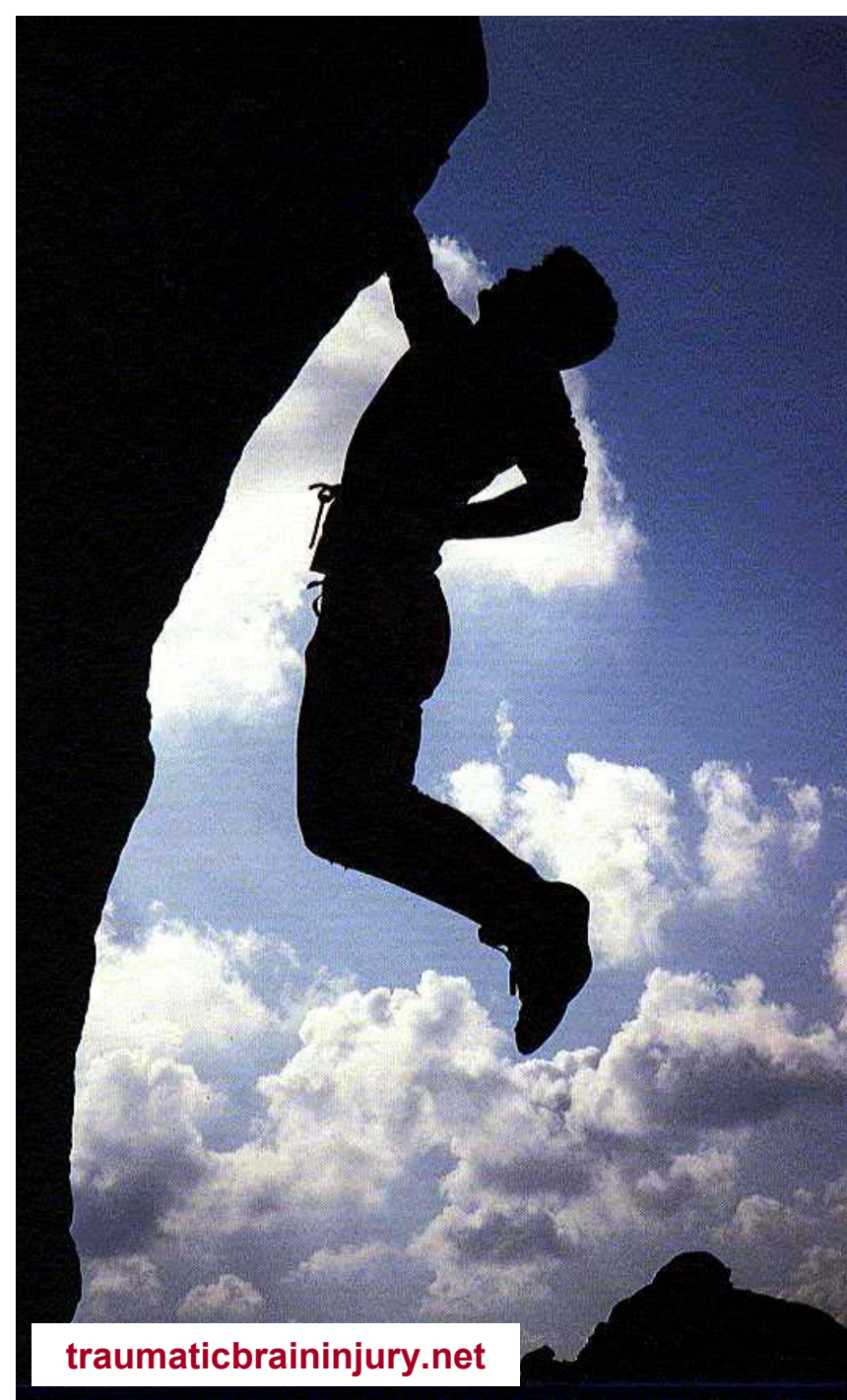
What Happens When Rehabilitation Ends?

Social Role Issues Ten Years Later

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A silhouette of a person climbing a rock face against a bright blue sky with scattered white clouds. The person is positioned on the left side of the frame, reaching up with their right arm. The rock face is dark and jagged, contrasting with the bright sky. The overall mood is one of challenge and achievement.

The return to home, family and community usually signals the end of formal rehabilitation. There are many complex issues which relate to the successful re-entry of the individual into their social roles with family, in the world of work, with friends and in the community. As we look at individuals over a ten year period, following the end of rehabilitation, there is much which can be learned from examining long term outcomes to improve the quality of life and to support individuals in maximizing their independence.

What is *Social Role*?

Activities and responsibilities that are related to different aspects of living.

- We are what we do
- Where have you been?
- What has happened to you?
- Are you like me?
- How do I feel about you?
- How do you make me feel about myself?

A large, light green silhouette of a person in mid-air, appearing to be jumping or falling. The figure is positioned on the left side of the slide, with its arms and legs extended. The background is a light, textured green.

What are the domains associated with social role activities?

- Personal life/primary relationships/intimacy
- Family life/parenting
- Friends/social network
- Work life/work performance/job satisfaction
- Socialization/recreation

What are the components of a social role?

- Level of participation in relationships with spouse, family members, friends, coworkers, neighbors and others.
- Ability to perform functions associated with role behaviors (e.g. being a parent)
- Ability to engage in activities required for specific aspects of life (e.g. being member of a team in the workplace)

A return to a satisfying and productive social role is a key component of a successful outcome

Factors associated with maintaining social role

- Positive family relationships
- Adjustment to disability by the individual
- Adjustment to disability by the family members
- Use of productive coping strategies
- Accessing resources
- Maintaining avocational activities and social network

Social Role: Changes in the Acute Phase of an Injury

What problems are likely to be encountered?

- Immediate physical, cognitive, psychological and behavioral changes
- Expectations of a return to pre-injury/”normalcy” status
- Dependence upon others and physical care needs
- “Medicalization” of disability
- Rallying of family and friends

Social Role: Post-Acute Rehabilitation Phase

What problems are likely to be encountered?

- Identification of needs and deficits which will persist
- Early confrontation of long term disabling conditions
- Modification of role function with family, friends and work
- Modification to living situation
- Withdrawal of some family and friends
- Impact of disability/deficits on functional capacities



Social Role Re-Entry: Return to home and community living

What are the issues and problems likely to occur?

- Changing roles and responsibilities for the person with TBI and their family members
- Extension of rehab into the home and life activities forces changes
- Accessing services in the community as a person with disability
- Difficulty in pursuing work and recreational activities



Primary Relationships and Social Role Difficulties



- Maintaining relationship with spouse/significant other related to disability issues
- Returning to intimacy
- Returning to caregiver, parent, family roles
- Addressing changes: divorce, job loss, role as a parent/caregiver
- Incorporating dependency and assistance needs into primary relationships

Family Aspects of Social Role Return



- Adjustment of individual, spouse, children, parents and extended family to revised role functions
- Perception of disability by family members
- Perception of changes created by disability
- Difficulty in returning to “old person/old relationship(s)”

Life Outside of the Home



- Withdrawal of friends following acute phase increases
- Feelings of isolation, loneliness, alienation
- Reduction in capacity to engage in activities
- Transportation and access issues
- Failure of others to understand brain injury consequences

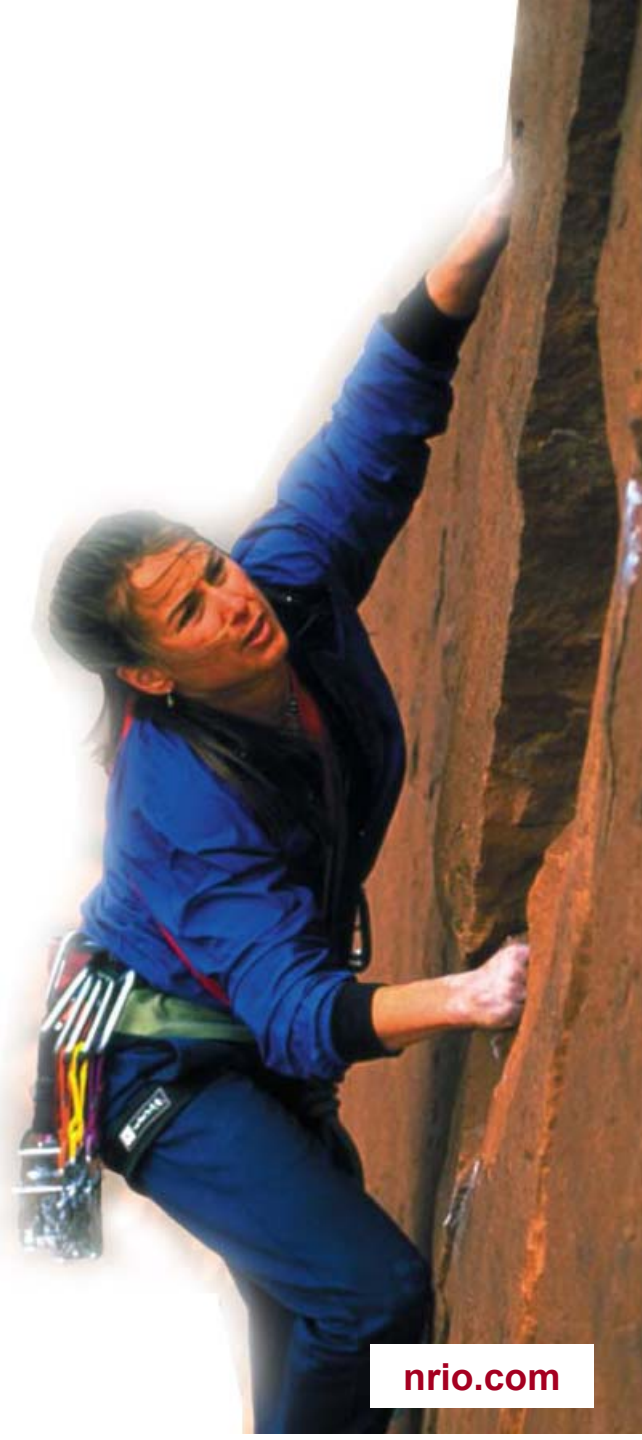
The Return to Work and School



- Perception of return by self and others
- Ability to perform and perception of performance by self and others
- Accommodations required for job/school participation
- Rejoining the social network at work/school
- Acceptance by supervisors, teachers, coworkers/peers

Parameters Studied in NRI/NRIO Outcome Studies

- Demographic characteristics: age, gender, ethnicity
- Severity Descriptors
- Length of prior acute and post-acute treatment
- Use of restraints
- Role of alcohol or other substances
- Comorbidity
- Type/mechanism of injury



Parameters Studied in NRI/NRIO Outcome Studies

- Discharge destination
- Level/amount of paid care
- Level/amount of family provided care
- Additional rehab services required
- Vocational/school return
- Avocational activity focus
- Level of return to pre-injury social role
- Interfering problems: Chemical dependency, psychiatric, other physical medical
- Community mobility
- Durability of outcome at: 3, 6, 12, 24+ month post discharge
- Comparison with prior periods and external studies

What are the Social Role Return Components Studied?

- Return to meaningful activity
- Return to home with minimal supports
- Re-assumption of pre-injury social role with spouse, family, friends, and co-workers without modification
- Response to change in level of dependence upon others including requiring assistance from spouse and family members
- Presence of psychiatric and/or substance abuse problems requiring intervention

Characteristics of the individuals discharged from NRIO

Source: NRIO Outcome Study, 1993-2003

	Avg. 1993-2002	Avg. 2003
Glasgow Coma Scale at Injury	3 (initial)	3 (initial)
Age at Injury	34.4 yrs.	43.8 yrs.
Duration of prior medical rehab	27 months	11.7 months
Gender	83% male	79% male
Educational Level (high school, college, grad., post-grad)	60%	62%
Prior Work History (employed/retired or previously disabled)	83%,17%	80%,20%
Role of Alcohol in Injury	33%	7%

Characteristics of NRIO/NRI Clients over a ten year period

Source: NRIO Outcome Study 1993-2002

NRI Outcome Study 1993-2003

- Greater severity of injury and related conditions
- Increase in age at time of injury
- “Sicker and Quicker”: reduced acute care stays with continuing medical care issues
- Reduced treatment intervals from injury to acute to post-acute to home
- Increase in comorbidity
- Decrease in financial resources available for rehabilitation

What are the levels of support required for social role return?

- Return to pre-injury status with in personal life (spouse, family, friends), return to work, recreation and avocational pursuits with no support services
- Return to pre-injury status with occasional supports (less than 2 hours per week)
- Return to modified roles with minimal supports (less than to hours per day)
- Return to modified roles with moderate supports (two to fours per day)
- Return to modified role with significant supports (more than four hours per day)
- Requiring total/full assistance/unable to direct care performed by others
- Requiring residence in care environment

Chronic medical problems affect social role function

Source: NRIO Outcome Study, 1993-2003

- Seizure disorders
- Respiratory problems
- Swallowing problems
- Skin Integrity
- Diabetes
- Circulatory problems
- Contractures and orthopedic
- Stoma care/GI complications
- Pain Management, headaches
- Fatigue



Priority Issues Reported by Family Members at the Ten Year Point

Source: NRIO Outcome Study, 1993-2002

- Physical limitations
- Chronic medical care problems
- Reliance upon others for assistance with basic care
- Transportation
- Psychological issues, such as: depression
- Cognitive (memory) problems
- Behavior problems (anger)



Future and Anticipated Problems from the Individual's Perspective at the Ten Year Point

Source: NRIO Outcome Study, 1993-2003

- Housing choice
- Return to living with parents or family members in a dependent status
- Difficulty in accessing services and activities outside of the home
- Obtaining and coordinating support services
- Finding resources with TBI expertise
- Economic changes

Physical Dependence of

Source: NRIO Outcome Study 1993-2002

- 1997 group reports “no change”
- 1998 group reports 18% decreased need
- 1999 group reports 35.6% increased need
- 2000 group reports 16.7% increased need
- 2001 group reports 8.8% decreased need
- 2002 group reports 22.5% increased need
- **Factors associated with increased needs: greater physical problems, equipment/orthotic need increased, emergence of “other medical/physical”, household changes**
- Increased severity of injury/disability effects physical dependence needs

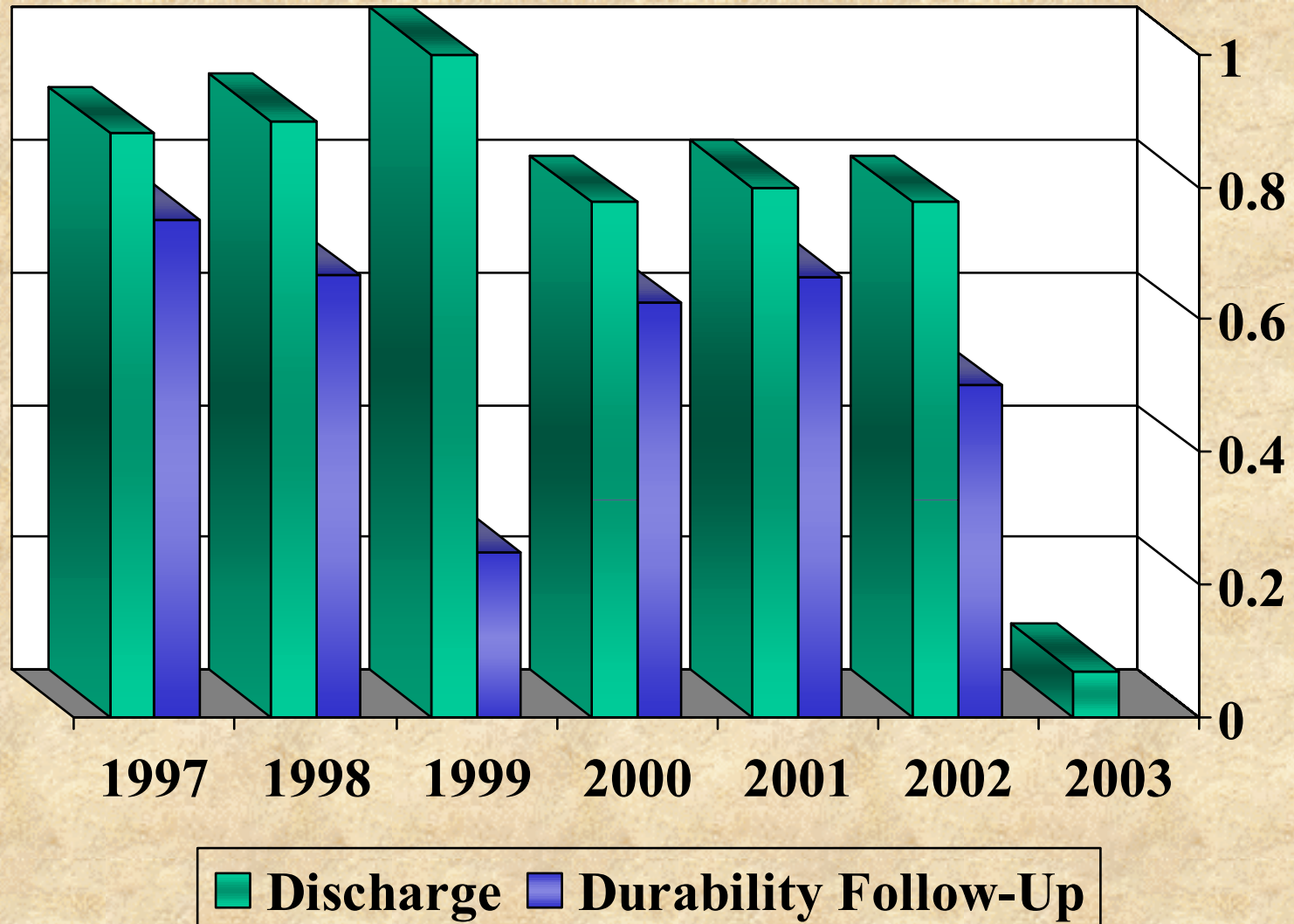
Return to Home with Minim

Source: NRIO Outcome Study 1993-2002

- 1993-2001 cohorts: 38.6% of the individuals discharged showed an increased and sustained capacity for independent functioning
- All cohorts showed a reduction in the number of paid support hours required per day
- **Factors associated with sustained independence and support reduction: learning of routines; self-cuing/regulation; use of strategies; pragmatic adaptation**

Aspects of Durability: Sustained Independence in the Home: Hours of Paid Support Required

Source: NRIO Outcome Study, 1997-2003



Issues in Family and Community Return at the 10 year point

Source: NRIO Outcome Study, 1993-2002

NRI Outcome Study, 1993-2003

- Increase in problems related to community mobility and access
- Increased service needs due to emergence of medical, psychiatric and other problems
- Altered social role within family
- Returning to home with aging parents or spouse
- Accelerated aging issues
- Sustaining meaningful life activities
- Maintenance of rehabilitation gains



Outcome factors observed relating to socialization and community living problems

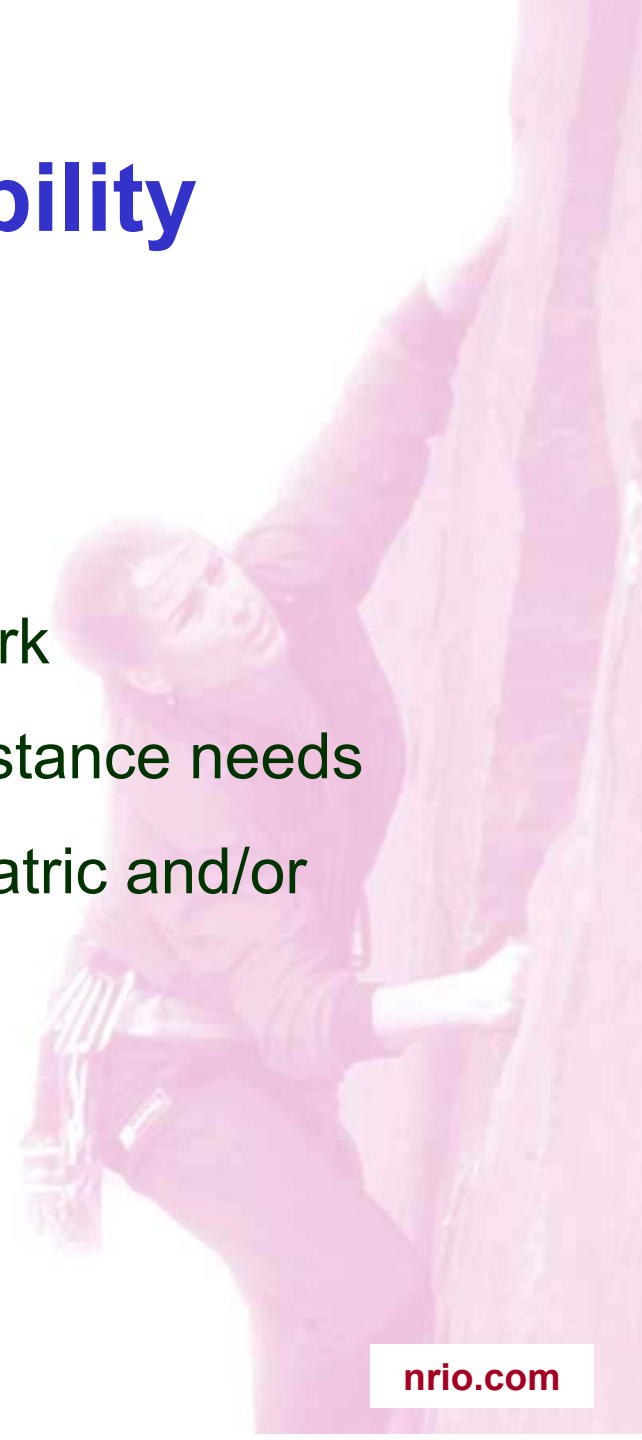
Source: NRIO Outcome Study, 1993-2003

NRI Outcome Study, 1993-2003

- Impact of social isolation and restricted community mobility
- Changes in social role occurring through divorce, separation and/or increased physical dependence
- Continuing psychological/psychiatric symptoms
- Role of cognitive problems, such as memory in maintaining positive relationships
- Amount of time and effort spent in the management of health problems
- Caregiver burnout

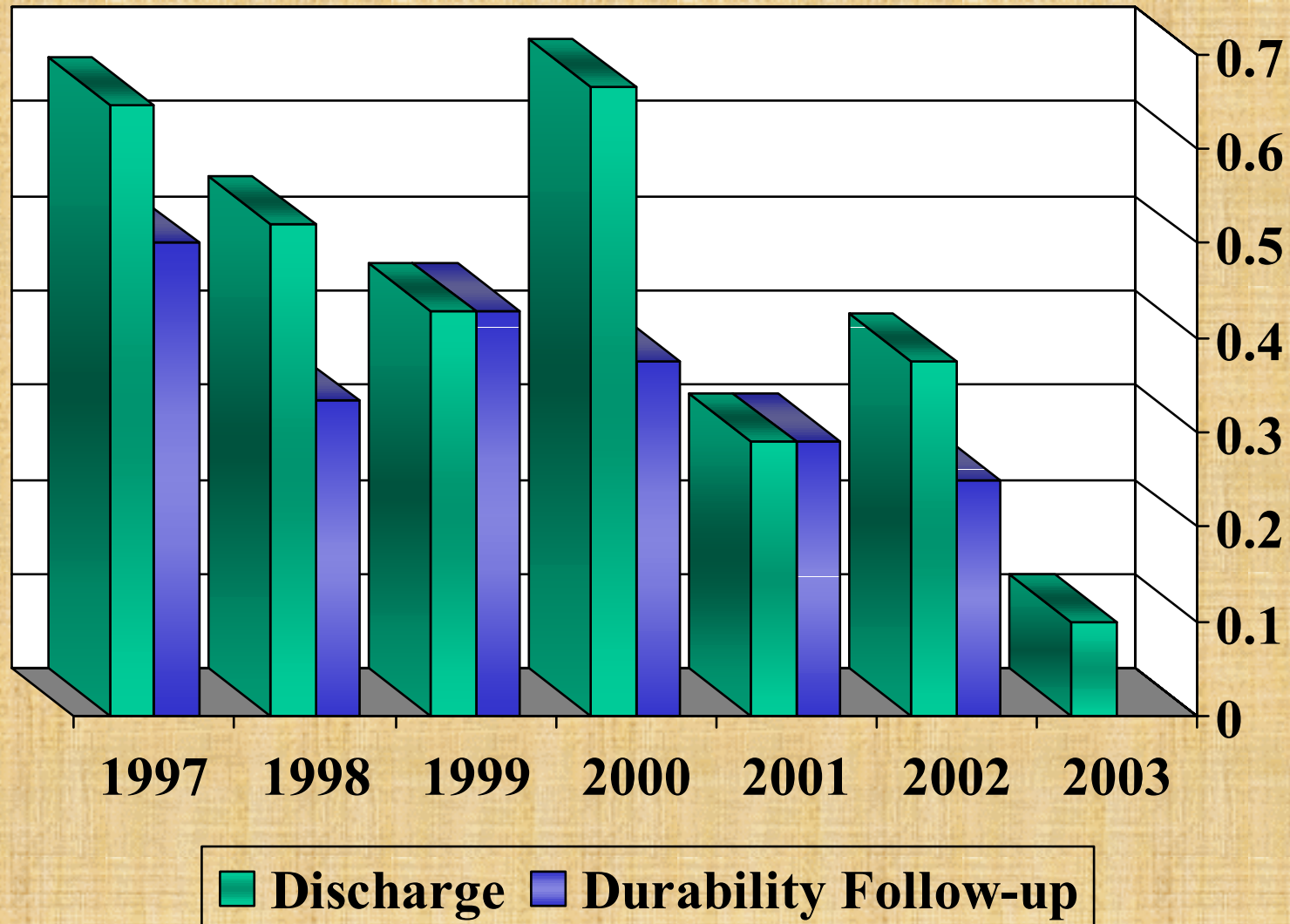
Social Role Issues: Durability

- Individuals reporting change/no change in primary social role
- Individuals demonstrating a return to work
- Individuals reporting an increase in assistance needs
- Individuals reporting presence of psychiatric and/or substance abuse problems



Aspects of Durability: Clients reporting “no change” in primary social role

Source: NRIO Outcome Study, 1997-2003



Return to Work

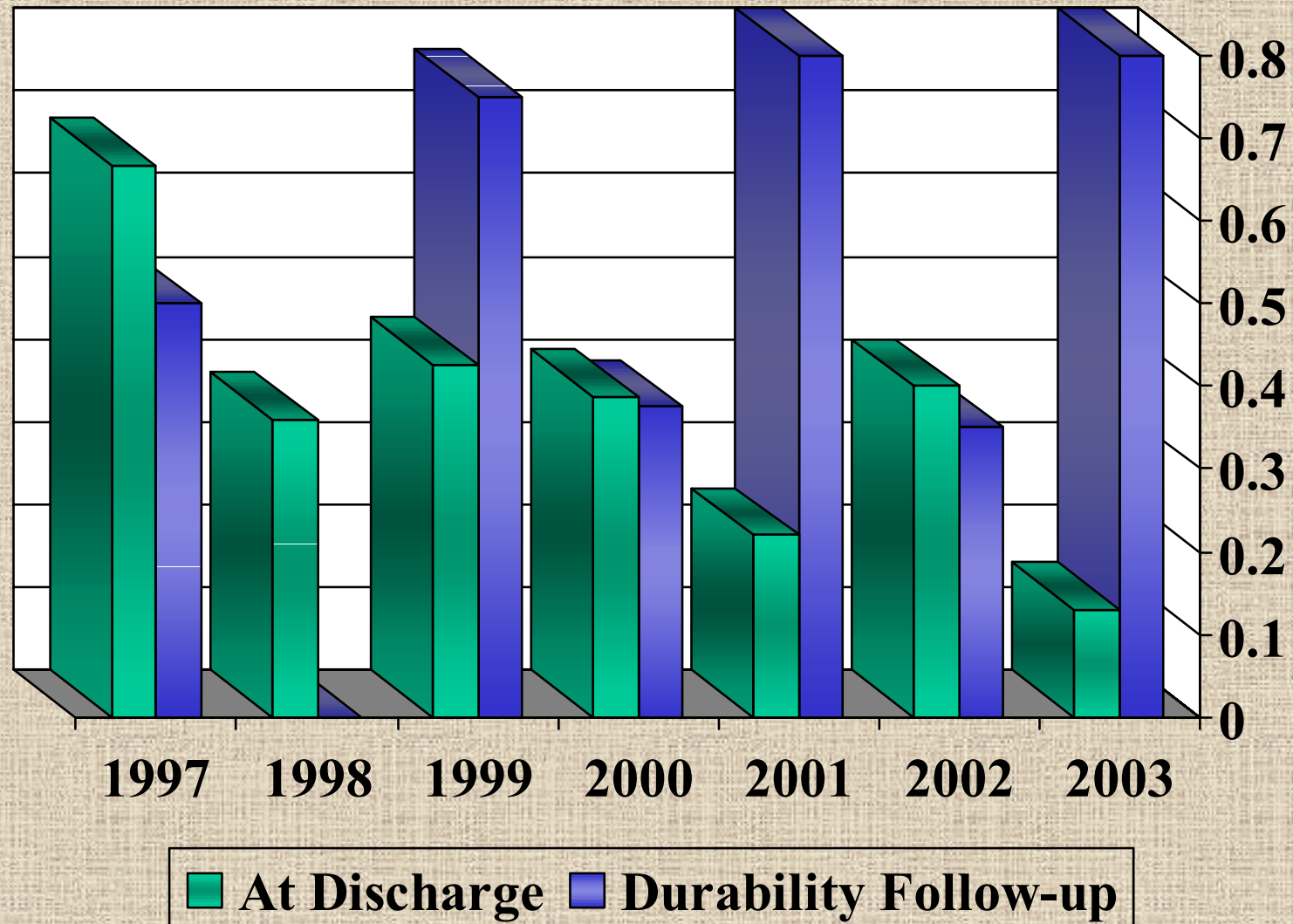
Source: NRIO Outcome Study 1997-2002 Durability Component

- 1997: 52% returned to work
- 1997 cohort in 2002: 38.7% remained employed
- **Factors associated with sustained vs failed employment: skills performance; cognitive problems; behavioral difficulties (anger) and psychosocial skills**



Aspects of Durability: Sustained Employment

Source: NRIO Outcome Study, 1997-2003



What are the barriers which are observed at the ten year point by the individual and family members?

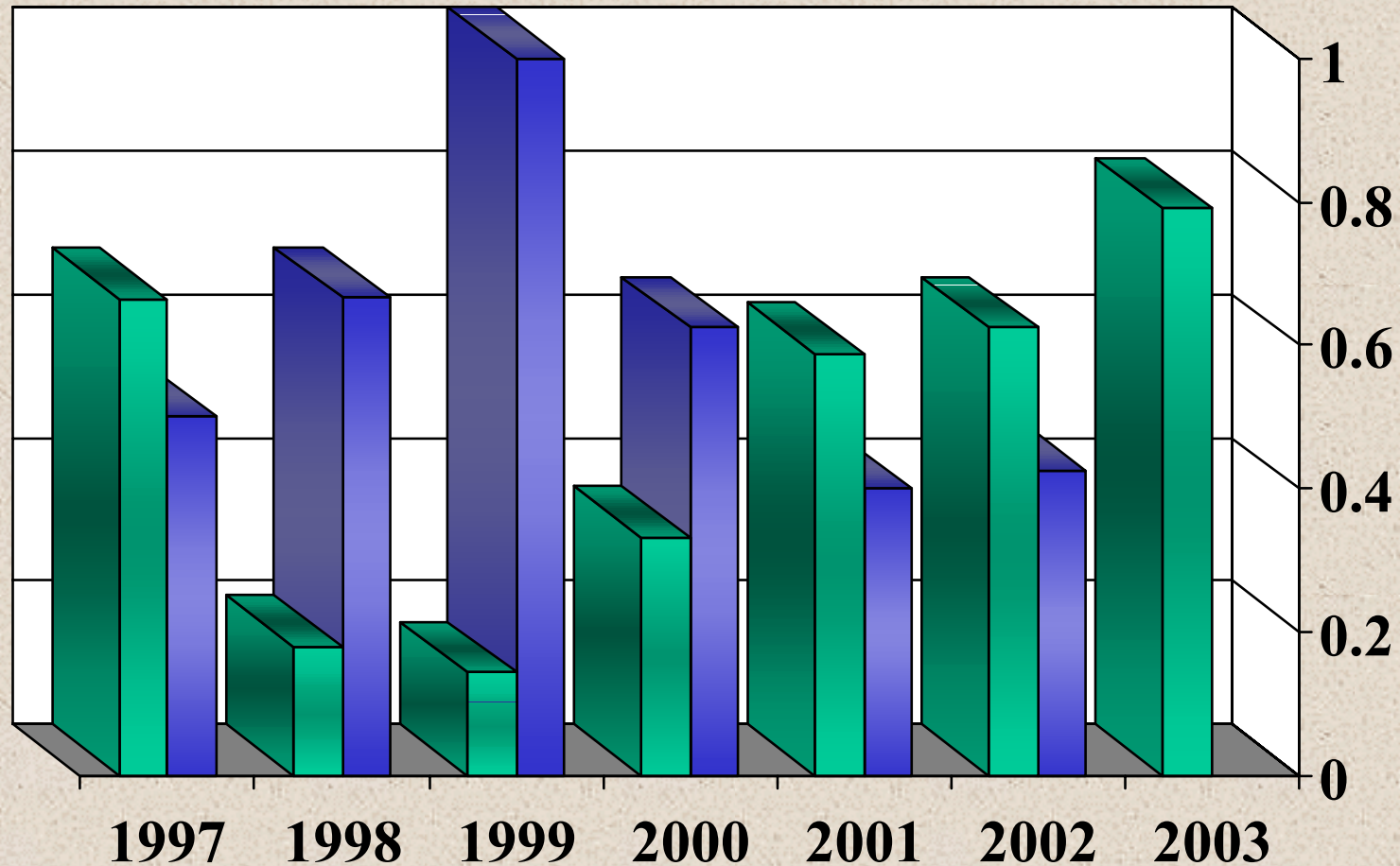
Source: NRIO Outcome Study 1993-2003

NRI Outcome Study 1993-2003

- Physiological decline and the onset of additional medical problems
- Independence in community mobility
- Ability to function within family and social network
- Self sustained activities (work, recreation, socialization)
- Persisting cognitive and behavioral issues
- Emergence/exacerbation of psychiatric and/or substance abuse problems
- Problems associated with aging and the onset of a physical decline

Aspects of Durability: Clients Reporting “Increase in Dependent Status” and “Requiring More Assistance”

Source: NRIO Outcome Study, 1997-2003



Family Response to Traumatic Brain Injury



Source: Sanders, 2003, Baylor College of Medicine, Institute for Rehabilitation and Research

Coping style and satisfaction with social support were more significant factors than injury severity in assessing a positive family response

Best predictors for positive family response were a low number of “unmet needs” and a low frequency use of “escape/avoidance” strategies

Family functioning is an indicator of adjustment to disability for both the individual and the family

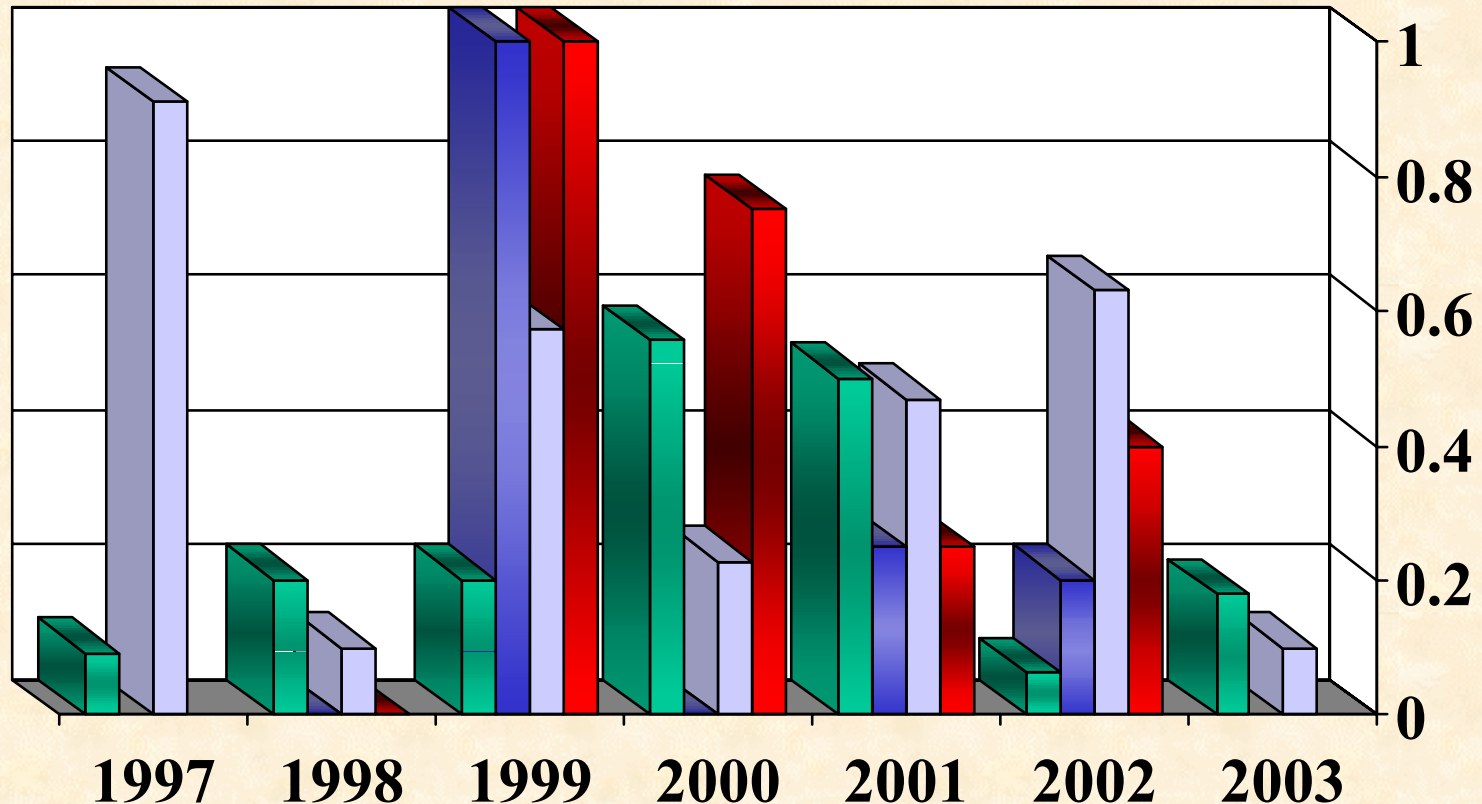
Individual and Family View of Quality of Life Issues

Source: NRIO Outcome Study 1993-2002

- Independence vs. Interdependence vs. Dependence: changes and shifts in values
- Ability to maintain social role with family, within marriage and with friends
- Ability to participate in high value activities (work, recreation, child rearing, church)
- Increased medical needs and sustaining rehabilitation gains
- Improved coping with changes and new problems

Aspects of Durability: Clients Reporting Substance Abuse and Psychiatric Issues

Source: NRIO Outcome Study, 1997-2002



Discharge Substance Abuse **Follow-up Substance Abuse**
Discharge Psych Issues **Follow-up Psych**

Behavioral Health factors associated with social role problems

Source: NRIO Outcome Study 1993-2002

NRI Outcome Study 1993-2003

- Increased likelihood of depression due to psychological and physiological determinants
- Potential for exacerbation/emergence of Bi-Polar Disorder, Mood disorders
- Increased potential for anxiety, PTSD, phobias
- Neurologic determinants of anger/rage problems
- Relationship of seizure disorders to irritability and dyscontrol events
- Effect of injury on pre-TBI psychiatric difficulties
- Medication non-compliance and self-medication
- Failure to respond to traditional psychiatric armamentarium

Discharge Destination of Individuals with a Dual Diagnosis at the Five Year Point

Source: NRIO Outcome Study 1993-2003

- Decreasing trend of returning home with minimal supports to 0% in 2003, 34% in 2002, 27% in 2001, 9% in 2000, 15% in 1999
- Decreased trend of returning home with moderate support to 7% in 2003, 11% in 2002, 37% in 2001, 27% in 2000, 27% in 1999
- Increased trend of discharge to supported/ assisted living 35% in 2003, 0% in 2002, 12% in 2001, 9% in 2000, 8% in 1999
- Increased trend of discharge to congregate living 29% in 2003, 22% in 2002; 7% in 2001, 32% in 2000
- **Factors associated with trend towards increased care needs at discharge: increased severity with greater residual medical care problems, increased age at injury; increase in behavioral, psychiatric and substance abuse co-morbidity; increase in separation/divorce/family alienation**

Emergence of Substance Abuse Problems

Source: NRIO Outcome Study 1993-2002

- 1997 cohort 23.9% increase in incidence
- 1998 cohort 0%
- 1999 cohort 0%
- 2000 cohort 0%
- 2001 cohort 13.7% increase in incidence
- Factors associated with incidence: pre-injury use; development of post-injury use; psychiatric co-morbidity
- Both 1997 and 2001 cohorts demonstrated greater comorbidity
- Greater injury severity factors noted in 1998, 1999, 2000 cohorts



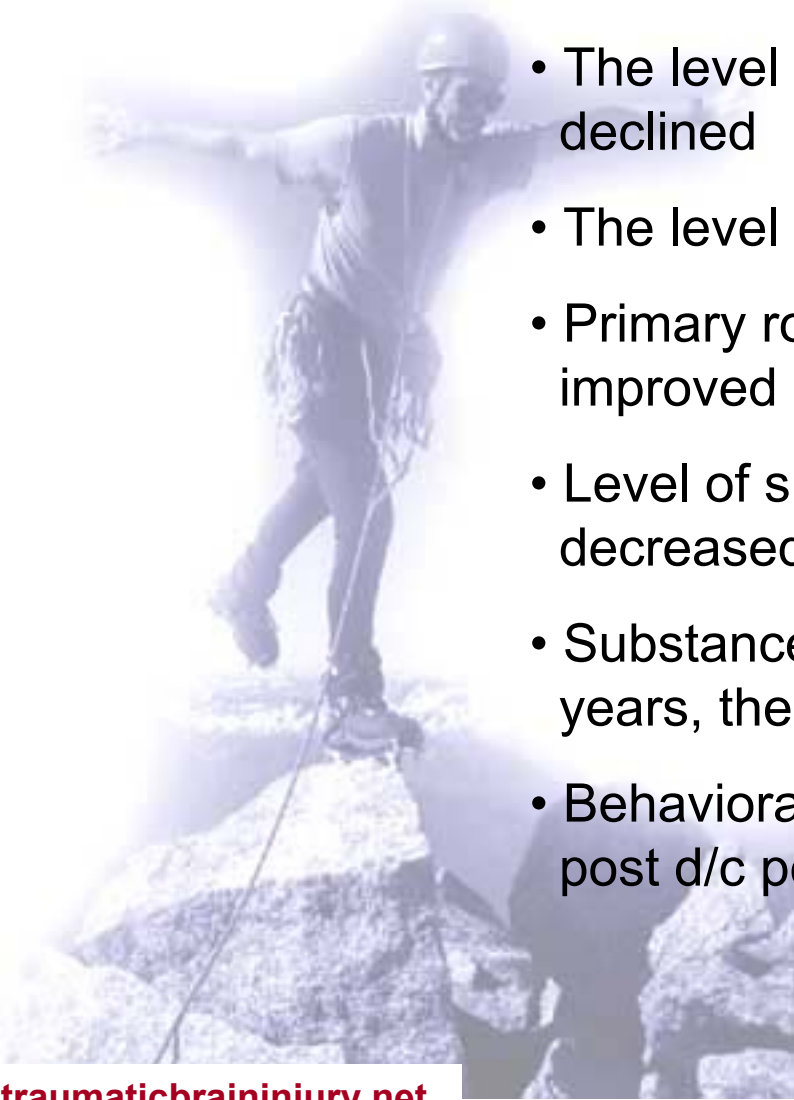
What's better at the ten year point?

Source: NRIO Outcome Study, 1993-2002

- Improvement in life quality as compared to past experiences in health care facilities
- Range of choices available
- Ability to self direct care and make personal decisions
- Return to family and loved ones
- Sense/feeling of independence
- “Getting on with life”

Durability Observations: 1997-2003

Source: NRIO Outcome Study, 1993-2003

- 
- The level of sustained competitive employment declined
 - The level of paid, in-home support declined
 - Primary role changes were maintained and improved over time
 - Level of supports required from family members decreased over time
 - Substance abuse problems increased in first two years, then declined in subsequent years
 - Behavioral health issues increased for a three year post d/c period, then declined

Five and Ten Year Benchmark Comparisons

Source: Kreutzer, Livingstone, Taylor, West 2003



Study included two groups:

- Mid term 5-9 years
- Long term 10-35 years
- Most frequently cited “obstacles”
- Memory Thinking
- Vision
- Coordination/moving limbs
- Transportation

Individuals Reporting “Unmet” needs

Source: Heineman, Sokol, Garvin, Bode, 2002



- Assistance with problem solving 52%
- Increasing income 51%
- Improving job skills 45%
- Opportunities to socialize 42%
- Increasing educational level 40%
- Managing stress 40%
- Managing money 35%
- Traveling in the community 15%
- Legal problems 22%
- Independence in housekeeping 25%
- Improving health 30%

What are the commonly reported difficulties encountered in social role return?

Source: NRIO Outcome Study, 1993-2002

- Maintaining pre-injury relationships with family, friends, co-workers, neighbors
- Returning to pre-injury pursuits: work, recreation and family life
- Explaining the long term effects of the injury, resulting disability and related changes
- Accessing services and activities in the community

What are the economic factors associated with social role difficulties?



- Reduction/loss of income, including among employed individuals
- Change in social status due to income level reduction
- Increased medical, living and personal expenses
- Increased stress secondary to financial hardship
- Increased financial dependence on others
- Diminished self-worth

What are the changes in living situations associated with social role problems?

- Return to spouse/family living in a dependent status
- Return to living with adult children or aging parents in a dependent status
- Moving to cooperative or shared accommodations with unrelated individual(s)
- Institutional care, nursing home, group home
- Problems with living situation, including homelessness

Social Return Difficulties

Source: NRIO Outcome Study 1993-2003

- **1993-2002 cohorts: 22.1% of the individuals experienced a decrease or deterioration in social role functions**
- Range: In 2000, 66.6% experience a decrease or deterioration. In 1998, 8% reported an increased or enhanced social role which has been sustained
- **Factors Associated with Social Role Changes: Increased physical dependence, emergence of behavioral problems, chemical dependency, emergence of mental health/psychiatric problems, divorce/separation**
- An increase in injury/disability severity has been observed from 1993-2002



Issues Associated with Aging

- Growing older with a disability, increased dependence on others
- Returning home to aging parents
- Returning home to an aging spouse
- Returning home to living with adult children
- Consideration of “out of home” care



Durability of Rehabilitation Outcomes

Source: NRIO Outcome Study, 2002 and 2003

- Sustained employment declined
- Paid in-home supports declined
- Dependence on family members for care decreased
- Social role and social network problems increased
- Substance use problems surface in the 24-48 month period, then stabilized
- Behavioral health problems emerged in the 12-24 month period, stabilize and decline

Comparison with Ongoing Outcome Data

Source: Traumatic Brain Injury National Data Center, Traumatic Brain Injury Model System, Database Update, Millis, 2004

- **Marriage:** at the 1 year point 87% of the individuals married at the time of injury remained married, 70% at the five year point and 74% at the 10 year point
- **Residence:** at the 1 year point 96% of the group discharged home remained at home, 94% at the five year point and 93% at the 10 year point
- **Employment:** at the 1 year point 33% of those employed at the time of injury returned to work with further significant declines at the 5 and 10 year points
- **Satisfaction with Life:** 20% reporting “satisfied with life” on Satisfaction With Life Scale at 1, 5 and 10 year points

What are the realities that we see at the five and ten year points?

- Sustained employment & employability declines
- Marriages and relationships stabilize after two years
- Mental health issues stabilize at five years
- Substance abuse increases in first few years, then stabilizes
- Health care needs increase
- Aging/age related problems occur
- Housing, transportation and access to services increase
- Economic problems increase

Implications for Rehabilitationists

- What causes the long term decline in sustained employment and employability? Is employment a realistic long term goal?
- What supports can be identified for the spouse and family to address the increase in assistance needs?
- What responses to the increased health care needs can be identified? Can improved health status be sustained?
- What resources can be developed to assist individuals in coping with age related issues?



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