Aging of youth with special needs
Transition to adulthood and beyond

Transition from birth to late adulthood
Disablement model
Participation
Emerging adulthood
Shriners Hospitals for Children
SCI Pathophysiology

- Damage to spinal cord results from
  - Initial insult to spinal cord
    - Trauma
    - Vascular (ischemia or hemorrhage)
  - Secondary injury
    - Inflammation
    - Ischemia $2^\text{o}$ to vascular damage +/- edema
  - Chronic changes
    - Scarring
    - Cystic degeneration
SCI Manifestations

- Motor
  - Paralysis
- Sensory
  - Loss of sensation

- Autonomic
  - Bladder
  - Bowel
  - Sexual
  - Cardiovascular
Uniqueness of Pediatric SCI

• Children who sustain a SCI have a relatively long-lifespan
  – Susceptible to secondary health conditions over a longer period of time compared to adult-onset SCI
    • Premature aging
    • Live with secondary health conditions for a longer time
  – Children are also susceptible to unique complications
Uniqueness of Pediatric SCI

- Children are not small adults
- Must take into account growth & development from infancy through adolescence into adulthood
  - Physical
  - Physiological
  - Psychological
  - Cognitive
Developmental Considerations
Physical

• Size
  • Weight
  • Bladder volume
• Neuro-Musculoskeletal
  • Growth plates
  • Linear growth
  • Scoliosis
Developmental Considerations
Physiological

• Heart rate
• Blood pressure
• Bowel and bladder function
A SCI impacts/interacts with all the psychological changes characteristic of each developmental stage
Developmental Considerations
Cognitive

Ability to communicate
• Symptoms of autonomic dysreflexia
• Expression of pain

Ability to learn/understand
• Self-catheterization
• Pressure ulcer prevention

Reasoning
The ultimate measures of success in caring for youth with special needs

Optimal participation and satisfaction as they progress through childhood and adolescence

Bottom line
They become adults with productive and satisfying lives
Goals for adults with pediatric-onset special needs

• Healthy
  – Physical
  – Emotional

• Independent
  – Living
  – Mobility
  – Autonomy

• Employed

• Participate fully in their communities

• Satisfying lives
Transition for youth with special needs
Challenges

• Challenges common to all youth
• Challenges common to most diagnostic groups
  – Environmental barriers
    • Physical
    • Attitudinal
• Disease/disorder specific
  – Cognitive
  – Physical
• Youth/Family specific
  – Personal factors
  – Socio-cultural
Challenges in caring for the child with a spinal cord injury

• Establish goals that evolve as the child matures and ultimately becomes an adult
  – Establish a sound foundation for a successful transition into adulthood that lasts a life-time
• Prevent complications
• Maintain focus on the big picture: full participation and satisfying life
• Both innovative and standard interventions must support this overarching goal
Developmental Trajectory

• Child’s development progresses in stages
• Each stage is a preparation for the next stage
• If a patient is to participate well in adulthood, they need to meet developmental milestones for participation at each stage
• One problem for CSHCN—don’t have developmental data about participation
Challenges in caring for the child with a spinal cord injury

• Need to have outcome measures that accurately assess key outcomes of an individual from injury as a child throughout adulthood

• Solid understanding of the natural history of pediatric SCI throughout their lifespan

• Identify risk factors for suboptimal outcomes throughout their lifespan
Transition

- Outcomes and different spheres of life
- The time-line
  - Developmental stages
Outcomes

- Education
- Employment/Occupation
- Living independently
- Mobility
- Participation
- Social development
- Sexuality
- Psychological functioning
- Health/Wellness
- Quality of life
Participation

ICF  WHO 2001

– Involvement in life situations
Participation
ICF-CY version 2007

- Learning and applying knowledge
- Communication
- Home life
- School life
- Social life
- Relationships
- Leisure & recreation

Context
- Capacity - ability to do
- Performance - what one actually does
- Environmental factors - facilitators & barriers
- Personal factors - gender
Capability

• Does the “capability” approach improve our understanding/measurement of participation at all ages

• Capability
  – Capacity
  – Opportunity
  – Choice
Choice

• Adults generally have a real choice in “participation”
  – Obligations-job, family

• Children may not have much of a choice
  – Much depends upon their parents
  – Parents may require certain activities
    • School
    • Chores
    • Music lessons
    • Religious education
Profound change in our approach to rehab and its goals

A more comprehensive approach with incorporation of disability models

- Impairment, disability and handicap
- WHO International Classification of Functioning, Disability, and Health (ICF) Model
WHO International Classification of Functioning, Disability, and Health (ICF) Model

Health Condition
SCI

Body Function & Structure
- Paralysis
- Pressure ulcer
- Depression

Activity

Participation

Environmental Factors

Coping

Personal Factors

Quality of Life
Went from fixing impairments to focusing on participation and life-satisfaction

• Standing → Meal preparation/Eye-Eye contact
• Walking → Mobility
  – Full participation in school and community
• UE interventions → Self-catheterization
Approach shifted from emphasis on short-term goals to long-term goals

Our management plan expanded to a grander time-span → the entire lifespan

• Transition

• Issues of aging
  – Preservation of function
  – Prevention of complications
Dynamic nature of growth and development throughout lifespan adds an additional dimension to the ICF

- Infants
- Toddlers
- Preschool-aged child
- School-aged child
- Early adolescence
- Late adolescence
- Emerging adults
- Adults
What is an emerging adult?

- 18-25 year olders
- No man’s land between the care-free adolescent and the adult with responsibilities
  - Job
  - Mortgage
  - Family
- May be the most tumultuous period of life after birth
What is an emerging adult?

- Exploration of possible life directions
  - Decision making with lasting implications
- Risk behaviors
  - unprotected sex
  - substance abuse
- Milestones
  - Education
  - Employment
  - Financial independence
  - Independent living
### A developmental perspective of the ICF model

<table>
<thead>
<tr>
<th>Stage</th>
<th>Mobility</th>
<th>Employment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Infant</td>
<td>Stroller / car seat</td>
<td></td>
</tr>
<tr>
<td>Toddler</td>
<td>Walking</td>
<td></td>
</tr>
<tr>
<td>Preschool</td>
<td>Walking / tricycle</td>
<td>+/- Chores</td>
</tr>
<tr>
<td>School-aged</td>
<td>Walking / bike</td>
<td>Chores/ Neighborhood jobs</td>
</tr>
<tr>
<td>Early adolescence</td>
<td>Walking / public transportation</td>
<td>Neighborhood jobs</td>
</tr>
<tr>
<td>Late adolescence</td>
<td>Motor vehicles</td>
<td>Community-based jobs</td>
</tr>
<tr>
<td>Emerging adult</td>
<td>Planes, trains &amp; automobiles</td>
<td>Summer jobs First real job</td>
</tr>
<tr>
<td>Adult</td>
<td>Planes, trains &amp; automobiles</td>
<td>Real jobs</td>
</tr>
<tr>
<td>Older adult</td>
<td>Loss of independent wheeled mobility</td>
<td>Retirement Volunteer</td>
</tr>
</tbody>
</table>
## A developmental perspective of the ICF model

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Participation/Socialization</th>
<th>Where</th>
</tr>
</thead>
<tbody>
<tr>
<td>Infant</td>
<td>Family</td>
<td>Home</td>
</tr>
<tr>
<td>Toddler</td>
<td>Playgroups</td>
<td>Home</td>
</tr>
<tr>
<td>Preschool</td>
<td>Playgroups</td>
<td>Neighborhood centers</td>
</tr>
<tr>
<td>School-aged</td>
<td>Sports and Scouts</td>
<td>Neighborhood</td>
</tr>
<tr>
<td>Early adolescence</td>
<td>Sports &amp; hanging out</td>
<td>Community</td>
</tr>
<tr>
<td>Late adolescence</td>
<td>Dating &amp; hanging out</td>
<td>Community &amp; beyond</td>
</tr>
<tr>
<td>Emerging adult</td>
<td>Partying</td>
<td>Community &amp; beyond</td>
</tr>
<tr>
<td>Adult</td>
<td>Marriage</td>
<td>Community &amp; beyond</td>
</tr>
<tr>
<td>Older adult</td>
<td>Senior citizen groups</td>
<td>Community</td>
</tr>
</tbody>
</table>
How can we improve transition for youth with special needs

- Understand the natural history of youth with specific disabilities
- Evaluate factors associated with good and not-such good outcomes
  - Develop specific interventions when feasible
  - Target high risk groups for interventions
Long-term Outcomes of Pediatric SCI

• Caroline J Anderson, PhD
• Kathy Zebracki, PhD
• Kathy M Chlan
Long-term Outcomes of Pediatric SCI

• Identify long-term outcomes of adults with pediatric-onset SCI
  – Independent living and driving
  – Employment
  – Participation
  – Medical complications
  – Mental health
  – Quality of Life

• Identify factors associated with these outcomes
  – Demographics, impairment factors
  – Environmental factors
Participants: sociodemographics

- 466 adults who sustained their SCI ≤ 18 y/o
- 63% males
- 54% tetraplegia
- 70% with AIS A
- Age of injury, mean = 13.9 (0-18)
- Age at follow-up, mean = 30.5 (24-45)
- Duration of injury, mean = 16.2 (6-38)
## Long-term Outcomes of Pediatric SCI

<table>
<thead>
<tr>
<th>Outcome</th>
<th>SCI</th>
<th>Census</th>
</tr>
</thead>
<tbody>
<tr>
<td>College education</td>
<td>40%</td>
<td>32%</td>
</tr>
<tr>
<td>Employed</td>
<td>60%</td>
<td>90%</td>
</tr>
<tr>
<td>Married</td>
<td>21%</td>
<td>41-65%</td>
</tr>
<tr>
<td>Live independently</td>
<td>64%</td>
<td>88%</td>
</tr>
</tbody>
</table>
Outcomes

• Habitation
  – 64% Live independently (i.e., not with parent)
    • 51% live with spouse or cohabitating
    • 12% have roommate
    • 34% live alone
Long-term Outcomes of Pediatric SCI

- Pressure ulcers: 33%
- Urinary incontinence: 34%
- Bowel incontinence: 13%
- UTI: 69%
- Hyperhidrosis: 15%
- Dysreflexia: 50%
- Spasticity: 44%
- Latex allergy: 10.5%
Long-term Outcomes of Pediatric SCI

- Shoulder pain: 59%
- Wrist pain: 27%
- Elbow pain: 19.5%
- Pain other sites: 51.5%
- Fractures: 5%
Long-term Outcomes of Pediatric SCI

- Hypertension/heart disease 6%
- Chronic medical conditions 22%
- Hospitalizations past year 22%
- Moderate-severe depression 8%
- Substance abuse 14%
<table>
<thead>
<tr>
<th>Condition</th>
<th>SWLS</th>
<th>CHART</th>
<th>Employment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pressure ulcers</td>
<td>+</td>
<td>+</td>
<td>+</td>
</tr>
<tr>
<td>Spasms</td>
<td>+</td>
<td>+</td>
<td>+</td>
</tr>
<tr>
<td>Shoulder pain</td>
<td>+</td>
<td>+</td>
<td>+</td>
</tr>
<tr>
<td>Incontinence B/B</td>
<td>+</td>
<td>+</td>
<td></td>
</tr>
<tr>
<td>UTI</td>
<td>+</td>
<td>+</td>
<td></td>
</tr>
<tr>
<td>Dysreflexia</td>
<td>+</td>
<td>+</td>
<td></td>
</tr>
<tr>
<td>Substance abuse</td>
<td>+</td>
<td>+</td>
<td></td>
</tr>
<tr>
<td>Elbow pain</td>
<td>+</td>
<td></td>
<td>+</td>
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<td>Wrist pain</td>
<td></td>
<td></td>
<td>+</td>
</tr>
<tr>
<td>Pain any site</td>
<td></td>
<td>+</td>
<td></td>
</tr>
<tr>
<td>Hospitalizations</td>
<td></td>
<td></td>
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</tr>
<tr>
<td></td>
<td>SWLS</td>
<td>CHART total</td>
<td>Employment</td>
</tr>
<tr>
<td>------------------------</td>
<td>------</td>
<td>-------------</td>
<td>------------</td>
</tr>
<tr>
<td>Marriage</td>
<td>+</td>
<td>+</td>
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<tr>
<td>SF 12 Physical</td>
<td>+</td>
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</tr>
<tr>
<td>SF 12 Mental</td>
<td>+</td>
<td>+</td>
<td></td>
</tr>
<tr>
<td>Gender</td>
<td>+</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Race</td>
<td></td>
<td>+</td>
<td></td>
</tr>
<tr>
<td>Income</td>
<td></td>
<td>+</td>
<td></td>
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<tr>
<td>ASIA motor score</td>
<td></td>
<td>+</td>
<td></td>
</tr>
<tr>
<td>Employment</td>
<td></td>
<td>+</td>
<td></td>
</tr>
<tr>
<td>CHART total</td>
<td></td>
<td></td>
<td>+</td>
</tr>
</tbody>
</table>
Predictive Factors

- Quality of Life (SWLS)
  - Female
  - Marriage
  - SF-12 Mental & Physical

- Employment
  - College education
  - CHART total

- Independent Living
  - Marriage
  - SF-12 Mental
Implications

• Medical complications are significantly associated with key outcomes of adults with pediatric onset SCI

• Therefore, preventing medical complications may improve outcomes
Implications

Establish expectations throughout the lifespan

• Healthy
• Independent
• Employed
• Participate fully in their communities
• Satisfying lives
The challenge in caring for children with SCI

- Prevent complications during childhood
- Because of long life span of individuals with pediatric SCI
  - Identify those at risk of complications
  - Develop strategies to prevent complications throughout their lifespan
Prevention of pressure ulcers

• Need to shift responsibilities from parent to youth
• Smoking prevention
• Nutrition
• Seating systems
  – Need to change with size of patient and their needs
Prevention of upper extremity pain

• Critical role of wheelchairs
• Developmental implications
  – changing size of wheelchairs
  – different needs
  – assessing and teaching proper propulsion
• Power versus manual
  – How to save those shoulders for 60+ years in a 10 year older
Transition

- Health care services and insurance
- Financial independence
- Education
- Vocational training and employment
- Independent living
- Psychosocial/sexuality
Transition and medical care

- Children and adolescents assume increasing responsibility as they grow older.
- Parents and care-providers progressively relinquish responsibility and control over their children and adolescents.
Transition and Medical Care

- Health care providers orchestrating these transitions
  - Establishing a game plan from the time of injury through adolescence and into adulthood
    - Developmentally based
    - Anticipatory guidance for patients and parents
Pediatric focus of care versus adult-focused care

- Maternal/paternal attitude of Pediatric care
- Adult care expects patient to be responsible
  - Being the primary communicator with healthcare providers, rather than the parents
  - Making and keeping appointments
  - Patients need to be decision makers
Birth to three years of age

- Encourage child to assist with activities
- Allow child enough time to complete tasks
- Parents need to talk with their child about his/her disability and abilities

Expectations
Three to five years of age

• Teach the child about his/her special needs
• Encourage participation in self-care
• Help child to interact socially in a variety of settings
• Assign chores
Six to twelve years of age

- Continue to assess child’s knowledge of his/her disability
- Continue to teach self-care skills
- Encourage attempts at self-care
- Encourage hobbies
- Allow child to begin participation in decision making
Six to twelve years of age

• Continue to assign chores or household duties
• Help child to interact with healthcare providers
• Talk about career options, interests…. “what do you want to be when you grow up?”
Thirteen to eighteen years of age

• Continue to assess teen’s knowledge and perception of his/her disability
• Discuss a plan for adult living including healthcare
• Encourage independence and time away
Thirteen to eighteen years of age

- Obtain information about state vocational rehabilitation program
- Encourage teen to find part-time employment
- Help teen to keep a record of appointments, medications, history, etc.
Thirteen to Eighteen Years of Age

- Allow teen to call to make own appointment
- Teach teen how to have medical records sent
- Discuss sexuality and dating
Emerging adults

- Assist young adult with finalizing adult healthcare services and financing
- Identify adult provider
- Schedule appointment with adult provider while still under pediatric care
- Transfer medical records
- Remain as a resource
Assure adequate preparation to ensure quality in adult life
Chicago Shriners SCI Team