

Mission Creativity: Unique Approaches to Transitioning

Sara J. Klaas, MSW, C-ASWCM

Patricia A. Mucia, RN, BSN, CRRN

Rebecca Vacco, MSW, LSW

Shriners Hospitals for Children, Chicago

Transition is.....

- The purposeful and planned movement of adolescents and young adults with special healthcare needs from child-centered systems to adult-based health care.
- It is multifaceted and attends to medical, psychosocial, and educational/vocational needs.

Why is transitioning important?

- Today, more than 90% of children with chronic disabilities/illnesses survive into adulthood (Blum, 1995).
- Children with special healthcare needs require uninterrupted healthcare services

Why is transitioning difficult?

- Fear factor
- Separation anxiety
- Difference in models
- Availability of resources
- Pediatric provider reluctance
- Preparation of the adult provider

What do you need.....

- Anticipatory guidance....

Healthcare professionals need to help families prepare for what comes next, at each stage of development and at the crucial time of transition to adulthood!

Key Elements for Medical Transitioning

- Knowledge of disability
- Knowledge of medications, side effects
- Participation in healthcare decision making
- Ability to direct care
- Process knowledge.... how do I get a prescription filled?? How do I make an appointment?? How do I get my medical records??

Key Elements for Resource Transitioning

- Post-secondary education and employment
- Housing
- Personal assistants
- Transportation
- Healthcare financing
- Community involvement

Age-Specific Transition Guidelines

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

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

Nineteen and older

- 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

Transition folders & resources

- Organized folder-system to assure all families have necessary information!
- Transition checklists and guidelines
- Teaching game

Unique Programs

- Camps
 - Sports
 - Quad
 - GLAHM
 - Diveheart
 - GLAHM
- Summer program
- Alumni connections
- Games group
- Transition apartment
- Transition week

The Long Journey Home

Patricia Mucia, RN, BSN, CRRN
Spinal Cord Injury Nurse
Coordinator

Transition to Home

- Preparation for going home after a Spinal Cord Injury involves:
 - Learning
 - Practice
 - Confidence
 - The whole family

Pediatric Spinal Cord Injury and Family Centered Care

- What is “Family Centered Care” and why is it important?
- Challenges post injury
 - ✘ Emotional Issues
 - ✘ Physical Issues
 - ✘ Medical Issues
 - ✘ Family dynamics issues

Pediatric Spinal Cord Injury and Family Centered Care

➤ Multidisciplinary team approach

- ✘ Core team members: nurses, physical therapists, occupational therapists, psychologists, social workers, pediatrician, dietician, recreation therapists/child life specialists
- ✘ Consulting team members: orthopedic surgeons, hand surgeons, urologist, neurologist

The Gap Between Hospital Care and Home Care

The Gap Between Hospital care and home care

↗ Furniture home like vs. hospital room

- ✘ Beds are normal height twin size beds with no electronic controls
- ✘ Dressers have some pull knobs
- ✘ Bathrooms are smaller than hospital rooms with tubs instead of roll in showers

The Gap Between Hospital Care and Home Care

The Gap Between Hospital Care and Home Care

↗ Distance Matters

- ✘ Emotionally separating from closeness of healthcare workers
- ✘ Feelings of isolation from new “family members”
- ✘ Distance is a required element of independence
- ✘ Safety and Security
- ✘ Location, location, location

Enhance Knowledge of the Transition Process

- ↗ Expectations of families while in apartment
 - ✘ Independent care of child
 - ✘ Ready for therapy on time
 - ✘ Meals in dining area independently
 - ✘ Get meds from nurse
 - ✘ Bowel and bladder schedule

Enhance Knowledge of the Transition Process

- Difficulties in transitioning home after injury
 - ✗ Hospital rooms are adapted for patients
 - ✗ Space restrictions at home vs. hospital
 - ✗ Full independence in care of pediatric spinal cord injury by parent and child
 - ✗ Coordinating working schedules and taking care of child

Enhance Knowledge of the Transition Process

- ↗ Requirements of family to be safe to stay in apartment
 - ✘ 24 hour care
 - ✘ Guidelines for Patient/Caregiver Staying in the Transition Apartment are...

- ⊕ Caregiver must be over the age of 18.
- ⊕ No overnight guests other than the caregiver.
- ⊕ The apartment is to be kept clean & tidy and bed made daily.
- ⊕ Report to therapy on time.
- ⊕ Maintain a reasonable sleep schedule in order to be rested for daily activities.
- ⊕ Return to the inpatient unit at designated times for medications and nursing services.
- ⊕ Hospital visiting guidelines apply, no children under the age of 6 years, no parties.
- ⊕ Meals are in the cafeteria.
- ⊕ Cooking in the kitchen is only allowed with rehab supervision, as a scheduled therapy session.
- ⊕ The use of alcohol, tobacco, recreational drugs will result in discharge from the hospital.

Enhance Knowledge of the Transition Process

- What happens while in the apartment
 - ✘ Families prepare child for therapy
 - ✘ Therapy and nursing assist families in working out kinks of home life
 - ✘ Questions arise
 - ✘ A routine begins
 - ✘ Cooking group

Enhance Knowledge of the Transition Process

- What the apartment helps families with related to discharge planning and transition
 - ✘ Space restrictions
 - ✘ Home schedule development
 - ✘ Confidence in independence of care
 - ✘ Smooth transition to the “real world”

Transition Week

An Intensive Educational Experience

Rebecca K. Vacco, MSW, LSW
Spinal Cord Injury Social Work
Coordinator

Purpose

- Transition begins early, but as “aging out” nears it can be very anxiety provoking
- Bring together all of the aspects of transition into one comprehensive week
- One final group activity before they move on to adult care
- Boost of confidence to become independent

Who?

- SCI patients ages 18-21
- Different educational and employment backgrounds
 - One high school senior
 - One community college student
 - One four-year college student
 - One participant thinking about community college
 - One participant thinking about returning to high school/completing GED
- Different experiences with independence
 - Three participants at home with family
 - One participant living independently
 - One participant living independently with family member as personal care attendant (PCA)

The Week

- Transitioning to Adult Health Care
- Dating, Relationships and Sexuality
- Independent Living
- Education
- Recreation
- Employment
- Socialization

Transition Worksheet

I have planned for my future:

- Spinal Cord Injury Care
- Urology Care
- Primary Medical Care
- Wound Care

I know how and am able to:

- Make my own appointments
- Refill my medications, catheters, and other supplies
- Describe my medical condition
- Perform my own medical care/daily treatments or know how to direct others to do so

Education:

- I know what I am interested in pursuing
- I am aware of my skills and strengths
- I have and know my education goals
- I understand my educational rights (504, IDEA, ADA)
- I am currently enrolled in an educational program
- I am interested in enrolling in an educational program and need help doing so

My immediate plans after high school or right now include:

- Full-time employment
- Community College or 4 year College
- Part-time employment
- Other

I plan to live with...

- Self
- Parents
- Other family members
- Campus dorm

I will rely on the following to provide transportation for me

- Self
- Family members
- Public transportation
- Other

Transition Worksheet

I will need transportation for:

- Shopping
- School
- Doctors' appointments
- Work
- Recreation

I will pay for my medical care with:

- Self pay
- Private Insurance
- Medicaid/Medicare
- SSI
- Other

I know how to manage:

- Paying bills
- Credit cards
- Checking account
- Budget
- Savings account
- Financial decisions

I feel I am able to:

- Ask for assistance when I need it
- Be interviewed for a job
- Plan an event
- Register a complaint
- Go shopping for clothes or groceries
- Talk on the telephone

I know the right way to communicate and interact with:

- Peers
- Friends
- Strangers
- An employer
- A boyfriend/girlfriend
- Teacher
- Sales person at a store

I would benefit from more information on:

- Insurance, Medicaid, or SSI Issues
- Independent Living
- Finding a School
- Vocational Rehabilitation or Getting a job
- College Disability Services
- Transportation
- Social or Recreational Activities

Transition to Adult Health Care

- Presentation by Sara Klaas-Director of Spinal Cord Injury Service and Patti Mucia-SCI Nurse Care Coordinator
- Differences between child and adult health care services
- Finding the right doctor for you
- Health Transition Checklist
- Condensed Health History
- SCI Research Lunch and Learn with Sara Klaas and Dr. Vogel

Dating, Relationships, and Sexuality

- Dinner and Discussion with Nick & Suzzi Fonner and Amber Sexton
- Safe place for participants to ask questions and talk about their experiences
- Key points centered around:
 - insecurities about body image
 - the importance of open communication, maturity, and being comfortable with yourself and your disability

Independent Living

- Housing, Personal Care
Attendants, Advocacy/Disability
Rights with Staff at Access
Living
- Grocery Shopping Combining
Logistics and Nutrition with Pam
Patt and Rehab Staff
- Managing Money, Banking, and
Credit: Illinois Treasurer's Office
Sharon Garchitorena-Senior
Financial Education Counselor

Education

- What to Expect on a College Campus presented by Trudy Goggin, Dean of Students at Dominican University
- College Searches: Applications and Scholarships

Employment

- Mock Interviews with Jim Pawlowicz, Director of Human Resources at Shriners Hospital for Children
- Mobility International USA (MIUSA) presentation by Becky Torres
 - Also combined employment and recreation
- Job Search Websites
- Myers-Briggs Inventory
- Resume Writing

Socializing and Networking

The conclusion of the camp was the SCI Alumni Reunion where the current patients were able to meet and mingle with past patients.

Evaluations

- Program evaluations were completed. Likert scale responses showed a “very good” (3.8/5.0) overall rating.
 - Participants found the dating, relationships, and sexuality workshop as well as the mock interviews as the most beneficial (4.6/5.0).
 - A very good rating (4.0/5.0) was noted for workshops on healthcare transitioning, travel, and money management.
 - Participants felt the information on college opportunities was least beneficial (2.3/5.0).

Conclusion

- It is important to recognize that the transition process is multi-faceted and does not simply focus on the medical component.
- It is essential to incorporate education, employment, recreation, dating, and overall basic, independent living skills.

Assure adequate preparation
to ensure quality in adult life
