Presentation Overview

- Welcome/Sharing your Transition Experience
- Health Care Transitions (HCT)
- Differences of Pediatric and Adult Health Care Systems
- Current State of HCT
- Barriers & Factors influencing HCT
Potential Outcomes of Unsuccessful HCT

Models of Successful HCT

Changing Roles of Professionals, Parents, and Youth

Supporting HCTs of Youth with Significant Cognitive Disabilities

Transition Tools & Resources
Operational Definition of Health Care Transition

A *purposeful planned process* that supports adolescents and young adults with chronic health conditions and disabilities to move from child-centered (pediatric) to adult-oriented health-care practices, providers, programs, and facilities.

Reiss & Gibson, 2004
What we know about Health Care Transitions (HCT)

- HCT critical but only part of becoming adult

- HCT involves:
  - Long-term planning
  - Long-term skill development

- Pediatric and adult medical systems two distinct cultures

- Interpersonal relationships critical
Differences of Pediatric and Adult Health Care Systems
Pediatric versus Adult

- Family-focus; parent as decision maker
- Parent as expert partner
- Supports development of skills; developmental orientation

- Patient-focus, confidentiality
- Physicians as expert
- Requires patient to be autonomous and competent; to function independently
### Pediatric versus Adult

<table>
<thead>
<tr>
<th>Pediatric Model</th>
<th>Adult Model</th>
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<tbody>
<tr>
<td>Multidisciplinary/team model with support services</td>
<td>Specialist consultation model; minimal support</td>
</tr>
<tr>
<td>Informal, relaxed, warm, optimistic interpersonal</td>
<td>Business-like, formal and judgmental</td>
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# Pediatric versus Adult

<table>
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<tr>
<th>Pediatric</th>
<th>Adult</th>
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<tbody>
<tr>
<td>Child as whole person within family context</td>
<td>Primary focus on disease process</td>
</tr>
<tr>
<td>Flexible, individualized treatment approach</td>
<td>Standard treatment approach; procedure and lab-based</td>
</tr>
<tr>
<td>Active oversight and advocacy</td>
<td>Minimal oversight; patient responsibility</td>
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Current State of Health Care Transitions (HCTs)
No HCT services → youth drop out of regular care after leaving pediatrics

Barriers to transfer

© Reiss & Gibson
No HCT Services  youth drop out of regular care, but use adult services intermittently

© Reiss & Gibson
No HCT services youth jump through logistical “hoops” and start adult care

Logistical “Hoops”

End Care

Mainstream peds care

Start Care

Mainstream adult care

© Reiss & Gibson
No HCT services youth start adult care, but do not continue with adult providers

Barriers to integration into adult care

Start of Care

Peds care

Adult

Return to Peds

No Regular Source of Care

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Barriers and Factors that Inhibit Smooth Health Care Transitions
Health System Factors

- No mechanism to transition youth, as a group
- Transfer not based on readiness or need
- Little networking among pediatric and adult health and related services (esp. MD’s)
Heath System Factors (cont.)

- Limited capacity of adult medicine in childhood onset conditions
- Differences in culture & practices in pediatric and adult medicine
Health Policy Factors

- Differences in financing and reimbursement of pediatric and adult health care
- No entity is responsible for improving systems for growing population of young adults with disabilities and SHCN (like Title V CSHCN Program)
Social Environment Factors

“Full adult” status not achieved by most until late 20’s (education, work, family formation, independent living, finances)
Social Environment Factors (cont.)

- Age-limits of health providers, facilities, programs & financing are out of sync with social reality of “emerging adulthood” status (age 18-30)
Youth, Young Adult, & Family Factors

- Youth & families not aware that move to adult system may be difficult
- Youth & families often not prepared for move
Youth, Young Adult & Family Factors (cont.)

- Young adults (& family) have limited capacity to interact successfully with adult system when transferred (knowledge & skills)
Potential Outcomes of Unsuccessful Health Care Transitions
Health Risks

- Adult primary and specialty care providers may lack interest in and experience with “pediatric” disease in adult life
- Inconsistency and discontinuity of care
- Reduction in amount, duration, and scope of health care services and supports
Adult system lacks familiarity with associated health risks (e.g. increased risk for cancer)

Loss of knowledge-base regarding the “natural course” of the individual’s condition
Stresses from Transfer

- Transfer experienced as rejection
- Transfer causes feelings of grief and loss
- Loss of peer group
Stresses from Transfer cont.

- Loss of formal and informal social supports for youth and their families
- Parents feel alienated
- Culture shock
Demands from Transfer

- Young adults (YAs) feel overwhelmed by new responsibilities: self-care, medical decision making, self-monitoring, self-advocacy etc.

- YAs need to unlearn successful pediatric adaptive behaviors and strategies
Demands from Transfer (cont.)

- YAs need to learn new “adult system” behaviors
- YAs confronted with “realities” of increasing morbidity and early death
Stress on Adult System

- Adult providers need to acquire new knowledge and skills to care for young adults with “childhood onset” conditions.
- YA patients may be challenging both clinically and interpersonally.
Stress on Adult System (cont.)

- YA patients may be uninsured or have public insurance (lower reimbursement rate)

- YA patients may have limited competencies
Models of Successful Health Care Transitions
Short Term HCT Services, including Support with Transfer, and Start Adult Care

- Short Term Preparation for Transfer
- Assistance with Logistics of Transfer
- Active Transfer
- Peds care
- Adult care
- Start of Adult Care
Long Term HCT Services, Transferred To and Start Adult Care

- Long Term Preparation for Transfer
- Active Transfer
- Implementation of Plan for Transfer
- Start of Care

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Changing Roles of Professionals, Parents, & Youth, in the Transition Process
<table>
<thead>
<tr>
<th>Stage</th>
<th>Professional</th>
<th>Parent</th>
<th>Child/ Young Adult</th>
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</thead>
<tbody>
<tr>
<td>1</td>
<td><strong>Lead</strong> responsibility</td>
<td><strong>Participates &amp; Provides</strong> care</td>
<td><strong>Receives</strong> care</td>
</tr>
<tr>
<td>2</td>
<td><strong>Partner</strong> Gives guidance &amp; support</td>
<td><strong>Full Partner</strong> Guides &amp; manages</td>
<td><strong>Participates</strong> in care &amp; decision making</td>
</tr>
<tr>
<td>3</td>
<td><strong>Consultant</strong></td>
<td><strong>Supervisor</strong> Shared decision making</td>
<td><strong>Manager</strong> Shared decision making</td>
</tr>
<tr>
<td>4</td>
<td><strong>Resource</strong></td>
<td><strong>Consultant</strong></td>
<td><strong>Lead</strong> Manages &amp; Supervises</td>
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Working Alliance

- Professionals, Parents, and Youth work together as an alliance in the transition process

- Professional initiates alliances
Characteristics of a working alliance:
- Trust & respect
- Liking
- Negotiated goals
- Negotiated strategies
- Negotiated roles and responsibilities
Stage 1: Professionals’ Roles

- Provide framework for promoting child’s growth and development
- Identify & acknowledge families’ values and priorities
- Affirm child’s/family’s strengths
- Develop plan based on shared goals
Stage 1: Professionals’ Challenges

- Let go of “professional model” of coping
- Let go of “professional” as only expert
- Accommodate to family coping
- Getting “caught in the middle”
Stage 1: Parents’ Roles

- Identify goals and priorities for newly diagnosed child
- Reexamine goals and priorities for self and family as whole
Stage 1: Parents’ Challenges

- Letting go of “perfect child”
- Letting go of guilt and blame
- Letting go of notion of “right” roles & responsibilities for mother and father
- Balancing needs of all family members (including couple)
- Keeping/developing vision for future
Stage 1: Child’s Role

- Child receives care
- May be involved in learning name of his/her condition
- May begin to assist in care
Stage 1: Child’s Challenges

- May begin to realize his/her differences from other children
- May begin to realize his/her limitations
Stage 1: Promising Practices

- Parent-to-parent support
- Role models
- Family movement
Stage 2: Professionals’ Roles

- Inform parents
- Empower parents
- Promote parent effectiveness
- Support evolving working alliance with parents and growing child/youth
Stage 2: Professionals’ Challenges

- Giving up need to “know best”
- Maintaining high expectations for child and future
Stage 2: Parents’ Roles

- Promote growing child’s/adolescent’s autonomy & capacity
- Guide & manage child’s/adolescent’s care
- Inform and empower
- Support child/adolescent in cognitive, personal, and social development
Stage 2: Parents’ Challenges

- Giving up need to “do it all myself”
- Maintaining high expectations for child’s and adolescent’s future
- Begin external shifts in care and support
Stage 2: Young Adolescents’ Roles

- Developing capacity and function as a participant in self care and decision making
- Increased responsibility for self-care
- Inclusion in decision-making
Stage 2: Young Adolescents’ Challenges

- Self-consciousness/anxiety about body shape, growth, and sexuality
- Concerns about being “normal” and “fitting in”
- Need to belong to peer group(s)
- Establishing emotional distance from parents
- Separating “help” from “support”
Stage 2: Promising Practices

- Professional provides guidance in care
- Professional provides support to family
- Care is family driven BUT youth guided
Family and professionals promote autonomy of young adolescent:

- Focus on individual’s goals, values, interests, skills, and needs
- Youth makes some decisions about his/her care and life
- Youth is involved in care
- Youth is safe and has emergency plan
Stage 3: Professionals’ Roles

- Professional as a “consultant”
- Deferring decision making to parents and adolescents
- Establishing separate relationship with adolescent
- Anticipatory guidance re: adulthood
  - Work
  - Autonomy
  - Independent living
Stage 3: Professionals’ Challenges

- Establishing separate relationship with adolescent (personal barriers, parent barriers)
Stage 3: Parents’ Roles

- Parents as “supervisors”
- Promoting adolescent’s “self-efficacy”
- Promoting adolescent’s “independence”
- Trusting adolescent in his/her decision-making
Stage 3: Parents’ Challenges

- Letting go of “my way is right”
- Maintaining “life” outside of needs of youth
- Accommodating to “normal” adolescent development:
  - Adolescent risk taking behavior
  - Adolescent’s need for “privacy”
  - Friends as confidants
Stage 3: Adolescents' Roles

- Developing capacity and function as the manager of self care and decision making
- Taking responsibility for taking meds, following routine, etc.
- Making independent decisions about care
Stage 3: Adolescents' Challenges

- Identifying personal assets and liabilities
- Making decisions and relying on own judgment and personal resources
- Establishing independent relationships with adults outside the home
- Having love/intimate relationships
Stage 3: Promising Practices

- Allowing adolescents’ independence
- Supporting adolescents in establishing relationships with other adults
- Supporting adolescents in their relationships with peers
- Allowing adolescents “safe” learning from mistakes
Stage 4: Professionals’ Roles

- Resource to young adult
Stage 4: Parents’ Roles

- Parents are consultants
- Respecting young adult’s autonomy
- Providing input and support as requested
- Assisting young adults in making good use of available resources and sources of support
- Focusing on self and new activities
Stage 4: Parents’ Challenges

- Letting “go”
- Accepting child as an adult
- Focusing on self and new activities
Stage 4: Young Adults’ Roles

- Taking responsibility for own care
- Making decisions independently
- Taking care of and creating independent adult life
Stage 4: Young Adults’ Challenges

- Setting and achieving educational, vocational, and social/personal goals
- Separating from parents:
  - Being financially independent
  - Living on own
  - Establishing relationship with significant other
- Establishing a system of mutual supports
Supporting Transition of Youth with Significant Cognitive Disabilities
Transition Supports

- Work with parents on future expectations and goals for adolescents
- Provide developmentally appropriate supports to youth
- Seek out cognitive based opportunities
Transition Supports

- Identify future formal and informal supports:
  - Guardianship
  - Trust Funds
  - Identify adult providers trained in providing care to young adults with complex needs/cognitive limitations
  - Identify day/vocational programs
  - Identify socialization opportunities
Transition Tools & Resources
Transition Plan

- What does it take to manage the special health care need to stay healthy?
Transition Plan cont.

- What are the special skills and/or knowledge necessary for independence and health?
  - What is my child (am I) responsible for now?
  - What does my child (do I) need to learn?

- What tasks will need to be addressed but given to others to carry out?
Health Care Transition Workbooks*

For ages 12-14, 15-17, 18+

- Thinking About Your Future
- Basic Knowledge
- Health Care Practices

* Reiss and Gibson (2005)
Health Care Transition Workbooks* cont.

- Meds, Tests, Equip & Supplies
- Doctor Visits
- HCT Tasks and Activities
- Transition to Adulthood
- Health Systems

* Reiss and Gibson (2005)
Transition Resources

- [http://hctransitions.ichp.ufl.edu](http://hctransitions.ichp.ufl.edu)
  Downloadable workbooks, checklists, videos on HCT

- [www.transitionmapde.org](http://www.transitionmapde.org)
  Downloadable workbooks, checklists, questions to ask adult providers, Delaware-specific database of adult providers
...if we wait for the moment when everything, absolutely everything is ready, we shall never begin.

Ivan Turgenev
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