Transition and Transfers: Adolescents & Young Adults with Complex Chronic & Progressive Conditions

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Objectives

- Story: A Transition Journey
- Define Transition vs. Transfers
- Identify relevance of well planned transition
- Discuss Successful *Transfers* to Adult Care
- Goals for Successful *Transitions*
- Factors for Successful *Transitions*
- Challenges
- Parental Role
- Transition Model: An exemplar
- References
A Transition Journey
“Transition” & “Transfer”
Why are these terms NOT synonymous?

**Transition:** A developmental stage that involves a significant milestone.

(www.transitions.canchild.ca/en/About Transitions/transitions.asp)

*i.e.:* Moving from a primary to a secondary school.
Moving from secondary school to the workforce.
“Transition” & “Transfer”
Why are these terms NOT synonymous?

**Transfer:** An act or process of moving someone or something from one place to another.

(http://www.merriam-webster.com/dictionary/transfer)

*i.e.*: An element of transition with a defined endpoint that may vary from person to person.
Why is a well-planned transition important? Who should be involved?

Unsuccessful transition = decrease health + increase in morbidity & mortality

Directly related to the lack of good adult follow-up care

EVERYONE should be involved in the transition process!
What makes a successful transfer to adult care?

• A primary care provider is vital!
• Availability of specialized adult providers
• A central provider to organize & oversee the process
• A portable medical summary
• Communication tools between pediatric and adult providers

What are the goals for having a successful transition?

1. Decreasing morbidity & mortality
2. Building capacity to participate in his/her own care
3. Building capacity to participate in his/her own community
4. Provide individualized, uninterrupted, coordinated care, collaborative
What makes a successful transition?

1. Optimization of the individual’s health prior to adulthood & availability of psycho-social supports:

   - Social worker
   - Career counseling
   - Life Skills counseling
   - Occupational therapist
   - Social worker
   - Psychologist
   - Physiotherapist
   - Nursing
   - Medicine
What makes a successful transition?

2. A central provider to organize & oversee the process
3. Initiation of a transition plan by age 12-14
4. Understanding the developmental readiness of the individual. (This necessarily may not correlate with chronological age)
5. Assistance with obtaining appropriate funding.
6. Advocacy group & government support.

http://transitions.canchild.ca/en/AboutTransitions/transitions.asp?_mid_=3224
Challenges of Achieving a Successful Transition

Adolescent Related challenges
Challenges to Successful Transitions
The Adolescent

1. The Brain (prefrontal cortex) = Executive Function
   - self-management and self-regulation not fully matured.

2. Chronic and progressive conditions: impaired executive functioning

3. Inability to envision the future & understand consequences

_Divecha, D. (2014) Nine big changes in young teens that you should know about. Developmental Science._
Challenges of Achieving a Successful Transition

Family
School
Community
Health System
Why does this matter for Adolescents and Young Adults?

The “Double Whammy”

Vulnerable: other physical & mental conditions, poor lifestyle choices.
Self-management and Self-determination: Is it possible?

YES!
Points to Remember when helping Teens and Young Adults

“Life ain’t in holding a good hand, but in playing a poor hand well.”

Alfred Henry Lewis

“Coach the young person in how to play the hand he/she has been dealt.”

Carl Pickhardt, PhD
What can parents do?

- Carefully read the psycho-educational assessment report.
- Model how to cope with situations and to be proactive as opposed to reactive.
- Teach how to be persistent without being obnoxious.

Strategies for parents & families to help

Four strategies which may help:

1. Teach the choice/consequence connection
coping with the consequences of decisions
power of self-management
Strategies for parents & families to help

2. Assign more responsibility over time:

Medication refills

Ordering medical supplies.

Budgeting & banking
Strategies for parents & families to help

3. Partial parental management
   Make help more conditional

4. Share parental self-management strategies
   Share personal successful strategies
   Be “an adult model” for operating in the world

Transition Model

Paediatric Spina Bifida Clinic

Adolescent Transition Clinic

Nurse Practitioner

Young Adult Spina Bifida Transition Services

Primary Care

Adult Specialists

Community Primary Care Physicians

Adult Rehab

Broader Psycho-Social Supports

Holland Bloorview

Kids Rehabilitation Hospital

The Anne Johnston Health Station

Ontario's Community Health Centres

Les centres de santé communautaire en Ontario
Main Goals of transitioning

Decrease morbidity & mortality.

Self management and Self Determination
Enablers to a good transition & transfer to adult care Transition Program

• Adequate preparation of the young adult & parent

• Flexible transition timing

• Early introduction to the adult clinic

• No interruption of healthcare services

• Up to date medical summary that is portable & accessible
What makes a good Transition Clinic?

- Having a healthcare provider to attend to the unique needs of the population during the transition and to assume responsibility.
- Knowledgeable adult providers.
- Subspecialists
- Coordinated care
- Communication with client, family & providers.
- Case Managers
- Mental health support
- Vocational training.
- SW to assist with financial & social issues.
Team Members

**HBKR**
1. Nurse Practitioner
2. Developmental Pediatrician
3. Life Skills Coach
4. RN/RPN
5. Adolescent Medicine Physician
6. Urologist
7. Orthopedic surgeon
8. Occupational therapist
9. Physiotherapist
10. Social worker

**AJHS**
1. Nurse Practitioner
2. Life Skills Coach
3. Primary Health Care Team
Resources

Checklist

Transition Documents
Resources: Self Management App

Home Page
- All About Me
- My Health Information
- My Resources

My Care Team
- Dilshad - Nurse Practitioner
- Andrea - Psychologist
- Amy - Registered Nurse
- Kelsey - Life Skills Coach

Kelsey - Life Skills Coach
- Jennifer - Social Worker
- Kerri - Physio
- Rebecca - Occupational Therapist

No boundaries
References


• Rauen, K.K., et al., Transitioning Adolescents and Young Adults with a Chronic Health Condition to Adult Healthcare—An Exemplar Program. *Rehabilitation Nursing* 2013; 38, 63-72.

• Kingsnorth, S., et al., Implementation of the LIFEspan model of transition care for youth with childhood onset disabilities. *International Journal of Child and Adolescent Health* 2010; 3; 4-Special Issue, pp. 547-559.


Thank you.