Turn the Tide on Transition to Promote Participation

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Paris - May 23, 2019

Let's start the conversation

#hellomynameis

An introduction is key!

- Who you are
- What you are going to do
- Why that is important

Source: https://www.hellomynameis.org.uk/

Who are you?

- Person with a disability
- Family member
- Healthcare provider – children only
- Healthcare provider – adults only
- Healthcare provider – children & adults
- Researcher
- Educator
- Other

Source: https://www.hellomynameis.org.uk/
Life Trajectories

Outcome metrics

Triple Aim framework:

- population health
- healthcare experience
- cost

as proposed by a systematic review on measurement in Transition Care

Prior et al. 2014
Adult Participation & Health Outcomes

- Physical activity level (low)
- Pain
- Fatigue
- Anxiety
- Depression
- Living on your own (more with parents)
- Employment (lower rates)
- Relationships (fewer)

Critical gaps

- A paucity of longitudinal data (though evidence from long-term follow-up studies is emerging)
- No research addressing individualized, person-centred outcomes
- Rethinking participation levels versus transactional experiences, difficulties and need for assistance

What adolescents and adults say (experiences)

- Negotiating identity as a person with a disability
- Interactions with healthcare professionals
- Bringing together information needs (knowledge gap) and a person’s own expertise (lived experience)

Societal impact

- Increased emergency department visits & hospitalizations
- Burden for the young person and the family
- “Crisis of Care”
Transition Field

- Grown immensely to include models and programmatic interventions to improve transitions

- Challenges surrounding current transition programs:
  - Condition- or centre-specific
  - Not evaluated or evidence-based
  - Use of ‘home-grown’ measurement tools
  - Focus on transfer and not transition process

Let’s continue the conversation…

Transition is a developmental process

How was your personal experience with healthcare as an adolescent?

- Positive
- Neutral
- Negative
WHO- ICF Framework (2001)

Health Condition (e.g., CP, ASD)

Body Structure and Function

Activity

Participation

Environmental Factors

Personal Factors

Adolescent’s issues and feelings

Health Condition

Function

Activity

Participation

Environmental factors

Personal factors

Rotterdam Transition Profile

www.erasmusmc.nl/revalidatie/research/transition

Description of the RTP

- The RTP classifies an individual's developmental stage for domains of participation and health service.

Participation: Finances, housing, education & employment, intimate relationships, sexuality, leisure activities, and transportation.

Health Service: Service & aids, rehabilitation services, and care needs.

For each item below, please check off the one statement that best describes your current situation.

1. Education and employment
2. Finances
3. Housing
4. Intimate Relationships
5. Transportation
6. Leisure / social activities
Self-manage & adapt in the community

- Tasks that an individual must undertake to live well with one or more chronic conditions
- Includes gaining confidence to deal with
  - Medical management
  - Role management
  - Emotional management

Shared Management Model by Age
(1=100% managed by parent, 10=100% managed by youth)

Innovation for Participation

- An organizational tool consisting of 10 modules designed to promote self-management
- Personal Information
- Social Information
- Social Activities
- School Information
- Work Information
- Budget Information
- Personal Care and Life Skills
- Medical and Health Information
- Obtaining Information
- Sharing Information

YOUTH-KIT

- An organizational tool consisting of 10 modules designed to promote self-management

OCHCU

Freeman et al. CCHD 2014
 TRACE STUDY

Obstacles to Successful Transition

The lack of developmentally appropriate tools to assess child and family readiness for transition as a barrier to transition

- Informed by the Community of Practice on Transition to Adulthood:
  - Provincial Council for Maternal and Child Health (PCMCH)
  - Canadian Association of Pediatric Health Centres (CAPHC)
Methods

PRO instrument 3 step development approach:

- **Phase I:** Item Generation
  - What should we measure?

- **Phase II:** Item Reduction
  - Which questions are effective?

- **Phase III:** Psychometric Evaluation
  - Does the instrument work?

Mean Score by Age (p-values <0.01)

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MyTransition App

- MyTransition App
- The Apply-IT Study (2017-2019)
  - Pilot RCT
  - N= 36 (15 intervention, 21 control)
  - Age 14-18 years
  - Chronic Health Condition or Disability
  - See Poster EACD 2019
  - Thursday May 23, 16.45-17.30

ApplyIT Study

ApplyIT Study - Qualitative

• “The app is really user friendly. Like there wasn’t anything too challenging about using it. The only thing challenging was getting the information that I needed from my mom but other than that like super easy to input it all and keep it organized. It was great.”

• “I liked how it helped prepare me for going to the doctor’s by myself and gave me a confidence boost.”

• “It’s a really good tool to have and it makes the transition a lot easier. It keeps you a lot more organized. ... It was like a big reminder of what I should be doing on my own. ... This is adult care. ... Your mom’s not always going to be there to ask or answer questions of the doctor for you. You ... got to take charge of it.”

ApplyIT Results – Intervention group

ApplyIT Results – Control group

Transition is a transactional process
Turn the Tide on Transition

Source https://www.scnsoft.com/services/sharepoint/knowledge-management/framework

Back to the conversation...

- Build positive relationships & trust
  - Youth – Parents - Professional
- Create timely opportunities
  - Right, critical or opportune moment
  - Tools are important (I have shared a few)
- Tailor & integrate tools in care
- Experiences
  - Strength-based & Focus on the Future!

Take home messages

- We have made big strides in our care for teens transitioning to adulthood
- We need to shift our focus toward adolescent’s capacity to self-manage and to the things we can do to educate and empower them and their families to support healthcare transition & promote participation.
- Setting goals and fostering skills and knowledge in teens and families is an essential part of this shift.
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