Transition from Pediatric to Adult Care at BCCH: ON TRAC Initiative Projects

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NURS344 Synthesis Project Summary
ON TRAC Background: Transitioning Responsibly to Adult Care

**Purpose:**

“The Transition Initiative is a Provincial initiative supported by Child Health BC and 4 partner projects. The goal is to facilitate transition, preparation and transfer, for youth with chronic health conditions and disabilities (CHC/Ds) to adult care and ensure that transfer is successful, with youth engagement and appropriate continued attachment to primary care and specialist adult services.”

**Background:**

“The Transition Initiative developed from concern regarding the increasing numbers of youth with CHC/Ds surviving beyond the pediatric age group and requiring long-term care, and challenges for all stakeholders as transfer occurred. The BCMA policy Statement-Closing the Gap, Youth Transitioning to Adult Care in BC, December 2012 has 10 recommendations regarding improving transition services within British Columbia.”

(ON TRAC Briefing Note, 2013)
Our ON TRAC Project:
Family Tools for Transition

**Purpose:**
To create a framework for a web-based toolbox for parents and families with youth making the transition from pediatric to adult care.

**Methods:**
- Perform a review of current literature focused on the perspectives and needs of parents/families during the transition period.
- Engage with families who have experienced or are currently experiencing transition to gain further perspective and create personal connections to determine the needs of parents during transition.
- Compile qualitative data gained through a comprehensive literature review and parent focus groups to inform family needs to be addressed in a web-based toolbox.
- Create a framework for a web-based toolbox by identifying useful tips, activities, and internet links for families to access during transition.

**Outcomes:**
- Literature review and summary.
- Framework for parent/family online toolbox.
Literature Review Themes

Feelings identified by parents:
- Stress - surrendering control and developing trust in youth’s self-care abilities.
- Exclusion - youth take on more responsibilities and interact with healthcare providers without parents.

Challenges identified by parents:
- Lack of access to health care, professionals knowledge, and information causing uncertainty regarding transition process.
- Low level of understanding of adult medical system.
- Concern about connection between youth and their adult healthcare providers.

Support needs identified by parents:
- Preparation period for transition and transfer.
- Psychological interventions (eg. Family Therapy).
- Organizational peer support (eg. Networking events, monthly family activities, blogs).

Transitional care program requirements identified by parents:
- Include family/parent component.
- Strategies for parents to meet with adult health care providers.
- Self-care strategies.
Family Focus Group Themes

- Parents are concerned about understanding the adult medical system and the process of getting the appropriate referrals.
- Parents find that it is hard for their youth to form the same relationship and connection they had with their pediatrician with an adult specialist.
- Parents feel that their youth should be seen as a person, not an illness.
- Parents feel that networking with other parents of youth with chronic illness is important to discuss issues and concerns.
- Monthly parent/family groups and activities to support families and give youth opportunities to do fun/positive things with their peers so that they can build confidence.
- Parents feel there is a need to develop a communication system, such as emails or online blogging, to discuss concerns and issues.
- Parents are concerned that the current pediatric system encourages dependency on the health care team.
Family Focus Group
November 26, 2013
Parent/Family Transition Foci

- Self-Advocacy
- Self-management
- Social Support
- Educational/Vocational Planning
- Financial Planning
- Healthy Relationships
- Personal Health & Safety
## Healthy Relationships

| My youth can come to me with questions about sexual health. | Become an [Askable Adult](#) to help your youth feel more comfortable talking to you.  
When talking about sexual health use accurate information.  
Have a sense of humor.  
Know your values and boundaries.  
You do not need to know everything! Call [Sex Sense](#) if you have any questions!  
**Tips for talking about Sexual Health**  
If your youth does not feel comfortable talking with you about sexual health, help them find someone else.  
Check out these links:  
| My youth knows what to ask their healthcare provider about sexual health. | Your youth’s sexual health may be affected by their health condition so it is important your youth talks to their healthcare provider about sexual health.  
Review the activities with your youth before they go to their appointments. | The Family Care Book: EXERCISE: Sexual Functioning, Capabilities and Choices  
The Family Care Book: EXERCISE: Professional Resources – Questions to Ask |
The Parent/Family ON TRAC Website

- The web framework for the Parent/Family Toolbox is based on the framework for the existing, live website for the ON TRAC Youth Toolbox.

- Refer to the ON TRAC website to view the format for the Youth Toolbox, which will be replicated for the Parent/Family Toolbox.

Connections = Social Supports
Safety = Health & Safety
Voice = Self-Advocacy
Next Steps...

- Feedback from family focus group participants regarding the current, rough parent/family framework outline developed during this project.
- Final editing process and inclusion of parent/family component on existing ON TRAC website.
- Development of a separate self-care toolkit for parents/caregivers based on information gained through family focus group and literature review.
- Development of family discussion/support groups based on feedback from the family focus group.