Holland Bloorview Kids Rehabilitation Hospital

Strengthening practice through partnerships: Supporting parents of children born preterm as they transition from neonatal follow-up to developmental/rehabilitation services

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Background

- Parents of children with complex needs experience distress with transition from neonatal follow-up (NFU) to children's treatment centres (CTC)
- To date, there is limited evidence-based practices to support transition between NFU and CTC; interviews with parents confirm the existence of a chasm between individual site policies and best practices across the system
- Without addressing this gap, parents will continue to encounter distress, which cumulatively threatens early attachment and child development

Activity #1 – Ontario Practices Scan

Objective: To identify parent-focused transition practices for parents of children born preterm/acutely ill when transitioning from Neonatal Follow-Up Programs (NFUP) to Children's Treatment Centres (CTC).

Methods:

- Health care providers participated in an online survey and qualitative interviews
 Analysis:
- Descriptive statistics and conventional content analysis.

Results:

- 60 participants (17 sites) from diverse health disciplines completed the survey, and 14 (from 11 of 17 sites) participated in a follow-up interview.
- Enablers included knowledgeable practitioners, shared NFU/CTC services and parent engagement.
- Barriers included lack of time, understanding of roles, and parent engagement.
- Informal information sharing with parents was the most common practice; site specific practices varied.

Findings highlight the need to improve and bridge NFU-CTC transition practices for parents of children with complex health needs. No two sites were the same.

Bridging early healthcare transitions

Parents are looking for education, resources and peer support to be successful with transition of their child to rehabilitation



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Activity #2 – Best Practice Symposium

Objectives: To bring a diverse group together to

- (i) facilitate knowledge exchange/uptake
- (ii) prioritize and develop strategies to strengthen NFU and CTC practices

Methods:

- Families, health care providers, researchers, and experts from across the continuum of hospital and community services for neonatal /infant /complex care, joined together in a full-day symposium focused on improving early healthcare transitions for parents
- The symposium addressed the need for essential collaboration to co-develop priorities, jointly working together in the best interests of families - and informed by families with lived experiences that can help create a changed culture and services
- Activities included parent experience panel, written stories, presentations, experiential exercises and small-group discussions

Results:

- 70 participants felt highly engaged and had the opportunity to collaborate together
- Participants identified three priority areas of research to co-create better transitions:







DUCATION RESOURCES PEER SUPPORT

 Particular attention should be made to: shared communication tools and care plans between healthcare providers, being knowledgeable about each other's services and transfer-of-care, and parent needs, readiness, communication and peers

Implications for clients and families

- Parent-focused transition practices between NFU and CTC services is an important 'upstream' approach to strengthen family resiliency, parental engagement and partnership in care, and ultimately, better children's health and development
- The symposium offered families, clinicians, and researchers an opportunity to collaborate on setting priorities

Next Steps

 Study and symposium findings will be used to inform the development and testing of parent-centred transition interventions with families' continued engagement and input

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