Parents of children with complex needs

Particular attention should be made to:

- Activities included parent engagement.
- Barriers included lack of information sharing with families.
- Participants identified three priority areas of focus.
- Without addressing this gap, parents will continue to encounter distress, which cumulatively threatens early attachment and child development.

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/acute illness when transitioning from Neonatal Follow-Up Programs (NFUP) to Children’s Treatment Centres (CTC).

Method:

- 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.

Activity #2 – Best Practice Symposium

Objective: To bring a diverse group together to

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

Method:

- 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:

- Education
- Resources
- Peer Support

Implications for clients and families

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

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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