ISQua FELLOWSHIP IN ACTION

Creating a Community of Care

Establishing a Parent Peer Support Network for Pediatric Transplant Families

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Fellowship in Action Session

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Background & the Problem

Organ transplant saves lives — but the journey takes an emotional toll

Organ transplant in children is a life-saving intervention — but for families, it is often emotionally overwhelming.

Parents face uncertainty about the procedure, prolonged hospitalization, post-transplant care, financial strain, and fear of complications or rejection.

At the hospital, families consistently said the clinical care was excellent — but they still felt isolated and anxious throughout the journey.

Many parents said they would have valued speaking with a family that had already navigated the same journey.

Clinical Expertise

Healthcare professionals provide medical knowledge, treatment, and monitoring.

Experiential Knowledge

Families who lived through the journey carry a unique form of emotional insight and lived wisdom.

The Need

A gap between clinical excellence and emotional experience

Anxiety & isolation

Families navigated one of the hardest experiences of their lives largely alone.

Quality is more than outcomes

Clinical success alone does not capture the full experience of patients and families.

No structured pathway

No formal mechanism existed for families to learn from those who came before them.

Untapped resource

Experienced parents were a source of support that the system did not yet use.

How the ISQua Fellowship Inspired the Idea

Quality is not only about clinical outcomes — it is also about the experience of patients and families.

The single most important lesson the Fellowship reinforced.

The Fellowship showed that organizations achieve better outcomes when patients and families become active partners in care design and delivery — not passive recipients of it.

Fellowship Principles That Shaped the Design

- **Person-Centred Care**
- **Co-Production**
- **Compassionate Leadership**
- **Systems Thinking & Patient Partnership**

These learnings inspired a structured Parent Peer Support Network — transforming families from passive recipients of care into contributors to the transplant care ecosystem.

The Intervention: What We Did

Building the Parent Peer Support Network within the pediatric transplant programme

01

Recruit Volunteer Parents

Identified & recruited parents whose children had successfully undergone transplant.

02

Orientation & Training

Sessions on communication skills, confidentiality, emotional support, and boundaries.

03

Mentor Pairing

Newly enrolled transplant families paired with experienced parent mentors.

04

Monthly Support Groups

Jointly facilitated by healthcare professionals and parent mentors.

05

Parent-Led Resources

Educational materials addressing common pre- and post-transplant concerns.

06

Family Voice in Design

Parent representatives included in decisions on education materials & service improvements.

Who Was Involved

A collaborative approach addressing both clinical and psychosocial needs

Two of these voices — parent volunteers and families — were new to the design table.

Challenges Faced

Real obstacles in building trust-based peer support

Finding willing storytellers

Identifying parents ready to openly share their experiences.

Confidentiality & privacy

Addressing sensitivities around sharing personal health journeys.

Consistency of mentorship

Ensuring uniform quality across mentor-parent interactions.

Managing expectations

Clarifying the role and limits of peer support vs. clinical care.

How We Responded

- Structured training for every mentor before pairing
- Clear governance mechanisms and role boundaries
- Ongoing supervision by clinical & psychosocial teams
- Regular feedback loops from participating families

Outcomes

What changed for families after the network launched

Increased confidence

Families preparing for transplant felt more prepared.

Better understanding

Improved comprehension of the transplant journey.

Reduced isolation & anxiety

Families felt less alone in a difficult experience.

Deeper engagement

Enhanced family participation in care planning.

Strengthened trust

Closer trust between families and the healthcare team.

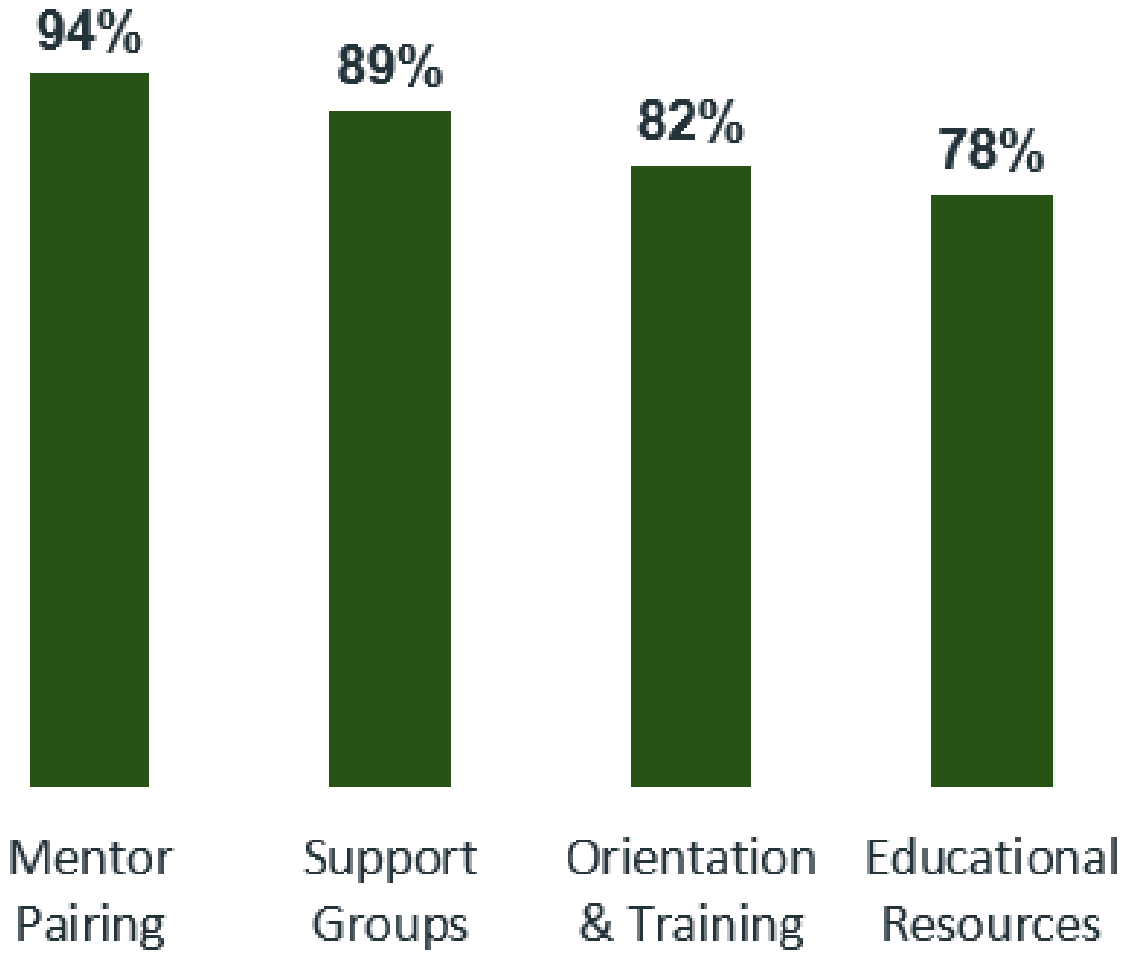
A lasting community

Support extending beyond the hospital setting itself.

"Speaking with another family who had experienced transplant provided reassurance and practical guidance that complemented clinical counselling."

Outcomes in Numbers: How Parents Rated the Network

Post-participation survey of parent-mentor pairs, % rating each activity "helpful" or "very helpful"



96% of parents said they would recommend peer support to another family

4.6/5 average rating of the monthly support group experience

87% felt "significantly less anxious" after their first mentor conversation

What We Learned

Compassion is most powerful when it is shared.

Families hold real expertise

Lived experience enhances care delivery in ways traditional clinical models cannot achieve alone.

Peer support builds resilience

Structured peer opportunities strengthen resilience, trust, and engagement for patients and caregivers alike.

Partnership beyond consultation

Meaningful partnership means genuine contribution to service design — not just being asked for input.

Plans for Capacity Building & Scale-Up

Growing from one programme into a broader community of care

Expand across specialties

Extend the Parent Peer Support Network to additional pediatric specialty services.

Virtual support groups

Reach families in geographically distant regions through virtual sessions.

Parent Advisory Council

Formalize family input into ongoing quality improvement initiatives.

Integrate into education

Embed parent mentors within patient & family education programmes.

Hub-and-spoke model

Connect transplant families across partner hospitals in a shared network.

From Recipients of Care to Partners in the Journey

The Parent Peer Support Network shows how principles from the ISQua Fellowship Programme translate into practical action — partnering with families and recognizing their lived experience as a resource that strengthens quality of care and community.

Thank you

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