

CONFERENCE ABSTRACT

Families as partners in care: A novel model of family engagement in children's rehabilitation and developmental services

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Introduction

In paediatric rehabilitation at Grandview Kids, integrated care begins at intake, with direct input from parents/caregivers, children and youth, to form the goals that will drive service provision. As practitioners continued to embed emerging best practices and policies to support seamless transfer between disciplines, families require additional support throughout their journeys. In 2012, Grandview Kids began the formation of a novel approach of a Family Engagement Team (FET) that is embedded into the development, implementation, and evaluation of daily practice.

Aims Objectives Theory or Methods

Through a series of lived experience interviews, this presentation will showcase the evolution of the Grandview FET to answer the question: "What are the actionable strategies for meaningful partnerships with patients and families?" The FET was founded on the principles that clients and families/caregivers are key partners in care and their voices must be embedded into programs, services, and decision-making processes. Strategies included: senior leadership support; investing in family leaders as employees or volunteers; shifting the focus from top-down to bottom-up engagement co-design with families; and embedding peer support referral process into models of care.

Highlights or Results or Key Findings

The senior leaders with support from the Board of Directors recognized parents/caregivers were more than "service users" but partners in the development, implementation, and evaluation of programs and services. A Family Facilitator Role was established as a full-time employee who led the development of a Family Advisory Council, an Online Parent Support program, and a Youth Advisory Committee. In 2021, the FET has seven paid employees that are current or past parents of clients or were clients, themselves. This expanded FET serve the function of capacity building (e.g., staff training, caregiver workshops, peer support), advocacy and citizenship (e.g., partnering across organizations to voice the needs of families of children and youth with disabilities), and

client and caregiver engagement (e.g., co-design of programs, contribution to accreditation). The FET has been successfully embedded into daily practice, with a formal referral process at any point of a client's journey (e.g., intake, assessment, transitions).

Conclusions

Parents/caregivers become true partners in care when they are embedded into the primary functions of the healthcare organization. At Grandview Kids, the FET has built trust among families and clinicians, bolstering a model of integrated care by establishing clear parameters to engage families as active participants in their child/youth's journey.

Implications for applicability/transferability sustainability and limitations

The Grandview Kids' FET will share their lived experiences developing meaningful partnerships with families. To begin, the FET must have support from the senior leadership, be willing to reach out to families to collect feedback, and be willing to act on the outcomes; the positive and the challenging.