

Parental perspectives an important consideration in development of tailored transition support and resources

OUR AIM was to explore the lived experiences of parents of chronically ill adolescents and young adults preparing for and experiencing the transition to adult care. We felt the parental perspective could positively inform our approach and help ensure a successful transition.

BACKGROUND – Traditionally, parents possess an intimate understanding of their child’s medical history, treatment regimens, and individualized needs. Yet, the experiences of parents remain markedly underexplored, despite their potential to be positioned as a critical resource for promoting successful transition to adult care, and mitigating transition-related adverse health outcomes (e.g., emergency visits, hospitalizations) among adolescents and young adults.

KEY FINDINGS – With proper engagement, clearly defined responsibilities, resources and supports, empowered parents play an important role in the transition care team.

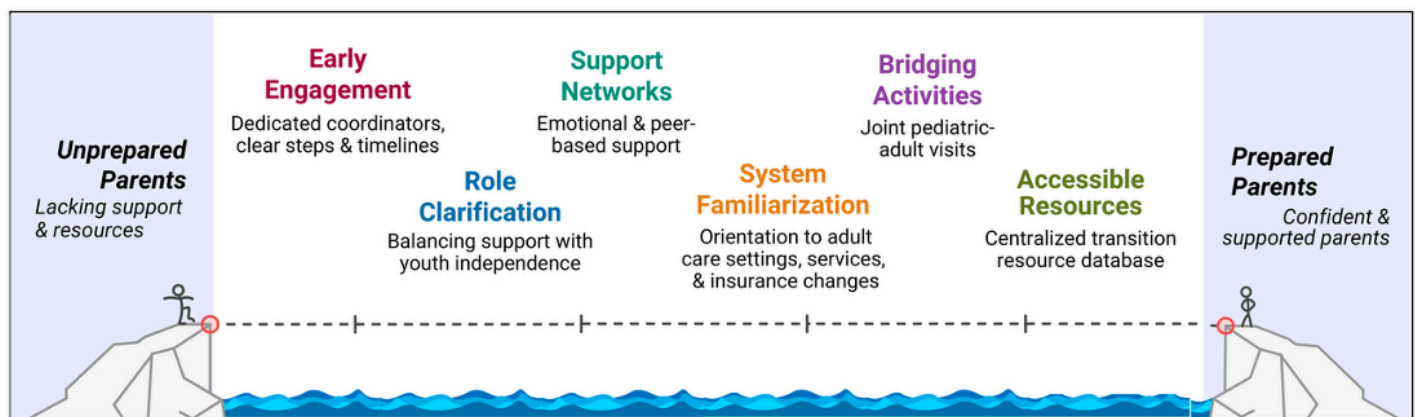


Figure 1. Literature-informed recommendations to support parental preparedness during healthcare transitions.

METHOD – This review was led by a group of patient and family partners affected by inflammatory bowel disease (IBD). In total, 54 studies were included in the review.

We followed PRISMA-ScR Checklist and Joanna Briggs Institute scoping review guidance to:

- Gather all studies related to the topic
- Categorize them (methods, populations, findings)
- Identify patterns, themes, and research gaps