

Co-creation of a transition resource for youth, families, & partners for the transition to adulthood

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Background

- The transition to adulthood can be complex. Youth and families face challenges with navigating new adult systems and finding opportunities for meaningful participation.
- Over the course of two years, a collective (members of Holland Bloorview's Family Advisory Committee, service providers, and stakeholders) co-created a new holistic transition resource to help clients and families feel more hopeful about the future.
- The goal of authentic and meaningful co-creation is often expressed, but not usually explored or operationalized in this context.

Research Questions

- What is the collective doing to co-create a resource that facilitates transition to adulthood and integrates best evidence, client and family voice, and clinical and system voice?

Methods

- We employed a Community-Based Participatory Research framework and mixed-methods:



Qualitative interviews with members of the collective at the start and end of the project



Paper archive review of documents (e.g., meeting minutes) related to the creation of the resource



Measured research team perceptions of the partnership using the Community Impacts of Research Oriented Partnerships (CIROP) questionnaire

- Interview notes, documents, and open-ended CIROP responses were analyzed thematically.

Clients, families, and service providers felt empowered by the process of co-creating a new transition resource to more meaningfully meet the needs of youth and families.

Results

- Five members of the collective completed the CIROP measure.
- Nine members of the collective participated in 13 interviews. We generated three preliminary themes shown in the figure below.

Embracing creativity and uncertainty

"It helped broaden my perspective about using a more creative process and enhanced how the [resource] has come about." - caregiver

"Letting go and having to engage differently, trusting the process." - service provider

"My assumption would be the clinician led the development of the [resource] and the family/youth were brought in as a contributor. We've flipped that, the family is driving this process through design thinking based on their expertise." - service provider

Future opportunities for community engagement

"There's a lot more that can be done to reach out to community partners and have them invested and meet halfway on that bridge." - caregiver

"I think it would be great to have more feedback . . . more community voices and more of the medical side with adult healthcare doctors and nurses." - service provider

"We were creating [the resource] together. It wasn't dictated from the top down so to speak." - caregiver

Shifting roles for service providers and caregivers

Conclusion and Next Steps

- Preliminary findings suggest clients, families, service providers, and stakeholders found the co-creation process empowering and effective in designing a new resource to support meaningful transitions to adulthood.
- Full analyses are ongoing. This research will help drive understanding of how healthcare organizations can work towards authentic client and family partnerships to enhance service delivery.