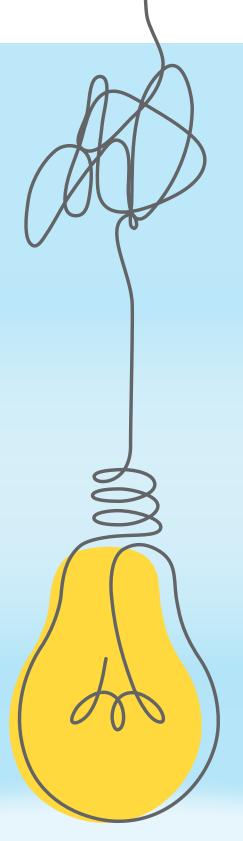
Kids Rehabilitation Hospital



Designing solutions for transitions

FROM CHILDHOOD TO ADULT LIFE FOR YOUTH WITH DISABILITIES

A guide for service providers, organizations, and system leaders

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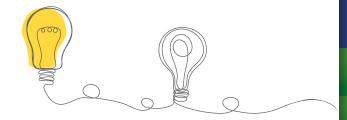
This Guide is a resource for service providers, organizations, and system leaders who are designing transition solutions for children and youth with disabilities and medical complexity and their families. It is not intended as medical or professional advice or opinion. Individuals are required to exercise their own judgment in using this Guide and application of any information contained in this Guide should be based on individual/patient needs, the relevant circumstances, and the local context. Neither Holland Bloorview Kids Rehabilitation Hospital (Holland Bloorview) nor any of the contributors to/authors of this Guide are providing medical, diagnostic, or treatment services through the information contained in this Guide.

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Land Acknowledgment

Holland Bloorview Kids Rehabilitation Hospital is located on the Treaty Lands and Territory of the Mississaugas of the Credit First Nation, and the traditional territories of the Wendat Nation, the Petun Nation, and the Seneca Nation, as well as a part of the Haudenosaunee Confederacy. This sacred land has been a site of human activity for 15,000 years and continues to be home for many Indigenous peoples from across Turtle Island.

In acknowledging the historical and contemporary importance of this land, we intend to honour the many ways of knowing and many experiences of truth that can exist in one place. We approach our community partners with openness to their many ways of being, and as part of our call to action to seek multiple ways of learning and different conceptions of 'knowledge'. We are grateful for the opportunities to have worked with many collaborators who have used their lived experiences to inform the contents of this Guide. Through this partnership and respect for the existence of many ways of learning, knowing, and being, we seek commitment to the principles of inclusion, diversity, equity, accessibility, and anti-racism.

This Guide may be used to design or build-up transitions supports for many different communities; our hope is that such transitions solutions are developed with the communities they are intending to benefit, and in a way that respects the breadth of their experiences and the histories of the people and the land. In doing so, we invite readers to consider the histories and meaning of the lands on which their endeavours will be realized (sample resource: Native Land).





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ACTION

Navigating the guide

Click on the tabs in the navigation bar to move from section to section. Words that are gray and underlined are hyperlinked to content within the guide. Words that are blue and underlined are hyperlinked to external websites. Click on the green arrows below to move from page to page.







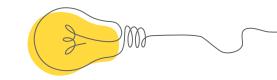
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Introduction

Holland Bloorview Kids Rehabilitation Hospital (Holland Bloorview) has a long clinical and research history of preparing children and youth with disabilities and medical complexity for transitions to adult life with a holistic and humanistic lens. We are trusted leaders and innovative partners in this field.

We specialize in:

- Early life transitions
- Friendships and belonging
- Life skills
- Youth engagement and leadership opportunities
- Employment participation
- Transitions to adult roles and adult systems



Over the past 10 years we sought to re-imagine and refine our approach to the continuum of care across the life span. We realized that transformational change was needed to support and empower the children, youth (including young adults), and families (the adults and siblings surrounding the young person's care, not including professionals) we serve within our organization and society, which includes a range of collective systems.

This guide was designed to help service providers (e.g., clinicians, educators, social workers), organizations (e.g., hospitals, schools, community agencies), and system leaders (e.g., managers, team leaders, senior management) across healthcare, community, education, and social services to support children, youth, and families as they experience transitions. Aspects of the guide will be actionable by individual service providers. Other aspects may have an individual champion and are better suited to action at the group or leadership level within organizations in broader sector systems. As you read through the guide decide what 'level' of action is best suited to your context.

What do we mean by transitions?

Transitions are life events and experiences marking a movement from one stage, system, or environment to another. They bring about substantial change in a person's life. These periods of change can be exciting and very stressful. Children and youth experience many age-related, healthcare- and school-based transitions as they grow up, with expectations of new roles and responsibilities (Miller, 2010).



While the broader societal understanding of the word "transition" can now be related to a transgender person, when this document uses 'transition(s)', we are not speaking to gender.









OUR CALL TO ACTION

Transitions from childhood to adult life, and the accompanying move to adult services, is a time of uncertainty for many youth with disabilities and medical complexity and their families. Embracing all the things young people and their families want to do as they realize their dreams while also managing their service needs is complex and can be challenging. While there can be excitement about new opportunities, some families feel a sense of uncertainty leaving the familiar support structure of childhood services. Other families may feel overwhelmed by the amount of preparation needed to navigate adult systems and supports that are still evolving to meet their needs. As families navigate these systems, it is important to be aware of and take action to address the intersectionalities of discrimination that may impact their access to services and their experiences in the systems more broadly.

The process of transition can be complicated by unmet needs, organizational and system barriers, which can make youth and families feel unsettled.

As a team, we reflected on how we could better support and partner with youth and families to prepare for transitions in ways that recognize and harness their strengths, and align with what is already working in their own contexts.

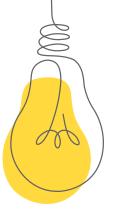
In 2017, we kicked off a 5-year strategy to boldly reimagine our existing transition practices thanks to donor funding. The Transitions Strategy was born out of the lived experiences of youth with disabilities and medical complexity and their families. It was informed by research that collectively called for innovations to improve the services, programs, interventions, resources, processes, and tools related to all elements of adult life. This includes early years services, entry to school, medical transfer, post-secondary education, employment, independent living, and community engagement.

Embracing this opportunity, our team set out to improve preparedness and planning, reduce barriers, and close gaps so that youth and their families can access more transition opportunities earlier and with greater confidence.





Our team of healthcare professionals, family and youth partners, clinical leaders, and researchers had the goal of designing new transition **solutions**. Guided by complex adaptive systems theory, we evaluated how transitions were experienced, facilitated, and made meaningful (King et al., 2022). We considered novel and creative ways to move beyond what had already been tried by being open-minded, curious, and were seeking ways to amplify youth, family, and community voices, make stronger connections, and gather new knowledge.



What do we mean by solutions?

A solution is a comprehensive, integrated, and timely way to address a need. A solution can be in the form of a service, program, intervention, resource, process, or tool. Solutions should address a transition challenge in a way that is engaging and context-specific, while remaining grounded in compassion (Vonderembse & Dobrzykowski, 2017).



As part of our process, we:

- Recognized that the solutions we created represent just the beginning of change.
- Acknowledged that healthcare, community, education, and social services are evolving.
- Accepted that as we achieve some changes, more change will be needed.
- Understood that not every solution will meet the needs of every youth and family.
- Appreciated that others may not share our vision to shake up how services are delivered.

Equity, Diversity, and Inclusion: Reflections from the Transitions Strategy Team

We work with children, youth, and families with diverse social identities of race, age, gender, language, socioeconomic status, and faith, as well as 2SLGBTQIA+ and newcomer communities. These groups may have a traumatic history with health, education, and/or social care sectors. Purposefully attending to and including the lived experiences of these groups are critical to the creation and implementation of equitable services.

Medical knowledge and social services more broadly are primarily informed by individuals and groups that feel safe sharing their stories and experiences within these health, education, and social care sectors. This is often people with the funds, social capital, cultural background, and language skills to support their attendance (often Western-born and white individuals), which does not reflect the breadth of who we see in our services.

In our context, we are committed to listening and working with children, youth, and families with different backgrounds, creating spaces for their voices to be heard. This moves us just a little closer to inclusion and understanding. When power is shared more often, service providers, organizations, and systems leaders learn more about different children, youth, and families and can integrate this learning as evidence informing practice.

Our commitment to and implementation of equity, diversity, and inclusion in our work is continually evolving. We have begun to consider the impact of individual, institutional, and structural racism, and the breadth of intersections that impact the children, youth, and families that we serve (particularly the impact of the intersection of ableism and all other forms of oppression). We continue to seek out and work with children, youth, and families that better represent those that access our services, purposefully embedding an equity, diversity, and inclusion lens to consider their needs.

Equity, Diversity, and Inclusion

Here are some resources that Holland Bloorview considers to shape our conversations and thinking:



- National Collaborating Centre for Determinants of Health: Let's Talk Intersectionality
- Government of Canada: Canadian Best Practices Portal on Social Determinants of Health
- Ontario Health: Equity, Diversity, and Inclusion Framework
- Wellesley Institute: International Review of Health Equity Strategies
- Health Leads: Social Needs Screening Toolkit



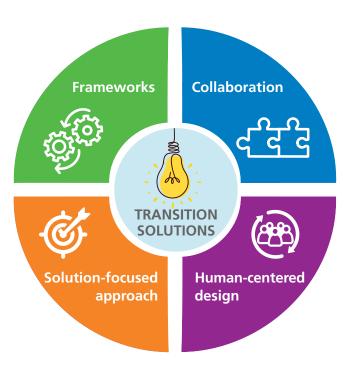


About this guide

The focus of this guide is to support service providers, organizations, and system leaders to start the process of building evidence-informed, needs-based solutions to influence transition to adult life experiences for children and youth with disabilities and medical complexities and their families. In this guide, we tackle the "how" firsthand through use of key tenets and tangible examples of how to support holistic transitions to adult life for children, youth, and families. It provides information on North American transition evidence and best practices, with an emphasis on the Canadian rehabilitation context. Note that our team is coming from a pediatric healthcare context and as such, information, examples, and resources are more likely to reflect this experience. We have included information from other sectors where possible and we encourage you to seek out information relevant to your sector as well.

Tenets guiding solution development

The guide introduces key tenets that have been essential to our work, namely the use of <u>Frameworks</u>, a <u>Solution-focused approach</u>, <u>Human-centered design</u>, and <u>Collaboration</u>.



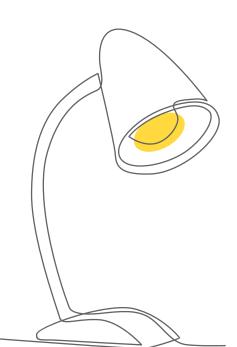
We embraced these tenets to understand experiences, explore possibilities, and innovate within existing resources to make large and small scale changes that ultimately change how we facilitate transition to adult life.

These tenets are not all-encompassing of our practice, but represent a foundational approach to understanding gaps, needs, and opportunities to tailor the creation of transition solutions (King et al., 2019; King et al., 2022; Morley & Cashell, 2017; Nilsen, 2015; Sandholdt et al., 2020). Tenets can be applied individually or in combination.

Families may experience significant differences in transition planning for: 1) children and youth who are developing their skills for self-management and decision-making; and 2) families with children and youth where they (the family) will remain the decision-maker throughout their child's life. The tenets can be applied to both situations.







Guide objectives

This guide:

- Identifies best practices and impactful frameworks to inform transition practice.
- Discusses the role of a solution-focused approach to generating practical solutions to real-world barriers.
- Describes the critical role that human-centered design can play as an approach to boldly reimagine transitions.
- Highlights the necessity of collaborating with children, youth, families, community agencies, organizations, and system partners.
- Provides tools and resources to support using the approaches outlined.

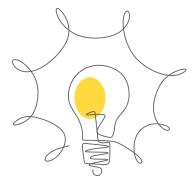
As you read this guide you will find:

- Definitions of important terms.
- Tips to enact the tenets within your own solutions.
- Examples of transition solutions that demonstrate how to apply the key tenets.
- Links to helpful resources.



Do you want to jump ahead to the examples?

Click on the examples tab in the navigation bar to read about how we have put the tenets into action!



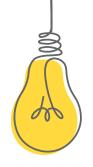
A note to readers:

Our approach and the results are illustrated in this guide. As you read through this guide, you may have new ideas, excitement, trepidation, or perhaps even discomfort. We hope that you will sit with these feelings and ideas, move through them, talk to families, colleagues, learners, and leaders. Consider what has prompted these feelings and ideas, and how you might use your realizations as springboards for change.





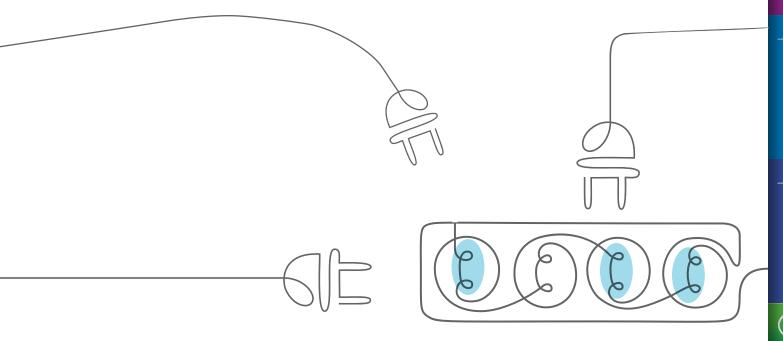
Supporting evidence and best practices



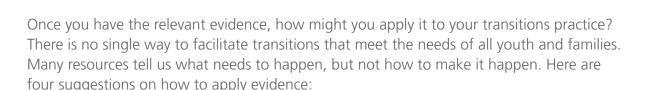
All of the work described in this guide is informed by different levels and types of evidence:

- Existing solutions are **evidence-based** when they have been studied through research and we know what they likely will and will not allow us to accomplish (Centre for Community Child Health, 2011).
- An **evidence-informed** approach considers research evidence, outcomes data, and lived experiences (service provider, children, youth, and family) to co-create new solutions (Woodbury & Kuhnke, 2014). This is followed by evaluation and research of the new solution to add to the current body of evidence for others to access and learn from. The solutions presented in this guide are in the process of gathering evidence regarding their effects.
- **Practice-based evidence** is established over time as we build expertise from experiences working with youth and families (Centre for Community Child Health, 2011). When you are designing new evidence-informed solutions you can draw upon your own practice-based evidence to inform development.

When preparing to implement practice changes, or to understand the current research that should be considered, often there is evidence that is already packaged in the form of practice guidelines, systematic evidence reviews, or standards of care. These resources have been vetted by experts in the field and they give an overview of the evidence that you will need to be familiar with for your practice.







TO START

The evidence tells us what needs to happen, so use this as a starting place.

TO SUPPORT

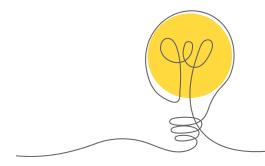
The evidence does not stand alone. When creating transition solutions, consider how the evidence relates to the needs and realities of children, youth, and families in your context.

TO INFORM

The evidence should be used to inform the creation of new solutions so that they start from a foundation of best-identified practices. Reviewing and evaluating existing transition programs and services can also ensure they are meeting the current standards and best practices for transitions.

TO CONTEXTUALIZE

Guidelines and standards of care provide the evidence, best practice, and policy to guide transitions-related decisions. This should be paired with the context provided by children, youth, and families as experts in their own experiences and service providers, organizations, and system leaders as experts in their field. This includes the diverse cultural capital that children, youth, and families, as well as service providers and system leaders hold in the system.





Exploring evidence and best practices

If you are beginning your journey into building new, evidence-informed solutions to influence transitions or if you would like a refresher on the most up-to-date evidence – first we suggest familiarizing yourself with packaged evidence from your field. As a starting point, we have identified four bodies of work (see Table 1) from Canada from a healthcare perspective that collectively represent evidence and best practice principles for different elements of transitions. If you are working in a different region or sector, these resources will likely be helpful and you may want to consider referring to local context-specific documents as well.

Table 1. A quick reference guide to supporting evidence and best practice resources

What are you looking for?

Foundational concepts on transition to adult life

Transitions resource

CanChild - The Best Journey to Adult Life: For Youth with Disabilities (Stewart et al., 2009)

About:

Specific to youth with disabilities, this resource provides a review of an evidence-based model and best practice guidelines, organized into three phases of the transition process: Preparation, Journey, and Landings in the adult world.

Value:

- Outlines the foundation for modern transition-related thinking and is helpful to understand where to start, why, and how the evidence supports this process
- Describes the roles of different stakeholders in the transitions process and consideration of transitions as a process over time

Practice standards for healthcare transitions

Health Quality Ontario - Transitions From Youth to Adult Health Care Services (Ontario Health, 2022)

About:

This quality standard is based on evidence and expert input across multiple disciplines. It focuses on youth aged 15-24 years transitioning from pediatric to adult healthcare services. This resource is intended for application to all clinical populations, including individuals with disabilities.

Value:

- Provides an overview of standards to be met for medical transfer.
- Offers prompts for reflection on whether transition services align with available research and practice-based evidence





Table 1. (continued)

A quick reference guide to supporting evidence and best practice resources

What are you looking for?

Practical guidelines to facilitate transition to adult care

Transitions resource

Canadian Association of Paediatric Health Centres (CAPHC) -A Guideline for Transition from Paediatric to Adult Healthcare for Youth with Special Healthcare Needs: A National Approach (CAPHC, 2016)

About:

This clinical practice guideline is organized by person-centered, clinical, and system-level transition considerations for youth 12-25 years. It is intended for application with all youth with special healthcare needs.

Value:

- Offers a holistic approach of transition and transfer through recommendations that consider healthcare system realities and transfer to adult medical services
- Provides tangible examples for conceptualizing a holistic, childrenand youth-focused transition within a complex healthcare system
- Applicable to transitions outside of medical transfers

Position statement from

a national perspective on facilitating successful transition to adult care

Canadian Pediatric Society - A Call for Action: Recommendations to Improve Transition to Adult Care for Youth with Complex Health Care Needs (Toulany et al., 2022)

About:

This position statement presents four core components of successful transition and six recommendations for successful transition practice in clinical, research, and advocacy areas. It was developed by a Canadian expert committee and draws upon the current literature. This resource is intended for application with all youth with special healthcare needs, including mental health.

Value:

- Provides a Canadian perspective on current transition evidence
- Highlights important policy and legal considerations for practice
- Calls for flexibility in age of transfer considering developmental readiness, improved integration of primary care in transition, and development of quality indicators to better evaluate outcomes

Transitions rapid evidence synthesis



RESOURCES

Generated through the McMaster Health Forum, this resource distills recent evidence about healthcare transitions, including a jurisdictional scan of Canadian programs and tools for children, youth, and their families:

• Identifying features of approaches to supporting transitions from child to adult care for young people with special healthcare needs (Voorheis et al., 2020) https://canchild.ca/system/tenon/assets/attachments/000/003/208/original/ supporting-transitions-rapid-synthesis.pdf



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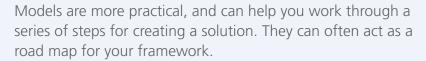


Why are frameworks important?

Frameworks help to explain concepts or factors that may influence processes for creating transition solutions and assessing their impact (Nilsen, 2015; Moore, 2018; Alberta Health Services, 2020). Frameworks can be used independently or in conjunction with other theories and models to help guide your work. They provide helpful structures for considering and applying the best practices, such as the resources in Table 1. This section will focus on using frameworks to optimize the transition solutions you are creating.

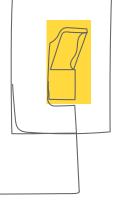
What do we mean by frameworks, models, and theories?

Frameworks present interrelating elements that, based on theory and evidence, are likely to influence an outcome. They can be used alone or in combination with theories and models to help achieve your transition solution.



Theories help to explain and predict what might happen as a result of the solution (Nilsen, 2015; Moore, 2018; Alberta Health Services, 2020).







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Using frameworks in creating transition solutions

Frameworks highlight essential elements (e.g., community engagement, family partnerships) to consider when creating transition solutions. Knowledge of these elements can help you to be more deliberate in planning your transition solution and stimulate thinking about what might be most helpful to meet the needs of children, youth, and families.

If you are at the beginning stages of your transition work, frameworks can help to anchor the solution, justify what may need to be included, and provide insight into how to ensure best practices are being considered and applied. If a transition solution already exists, frameworks can be used to update or refresh it for continued alignment with children, youth, and family needs, system realities, and identified best practices. Be mindful that these frameworks may not include the perspectives of children, youth, and families from diverse backgrounds, many of whom have a traumatic history with healthcare, education, community, and social services. It is important to choose and use frameworks with care.

When exploring frameworks to use, ask yourself:



What are you trying to achieve?

- Think about the rationale and objectives of your work, and reflect on:
 - Why is a solution needed?
 - Who is the solution for?
 - What will the solution accomplish and how?
 - How will you know the solution is successful?
- Different frameworks may serve different purposes in your process. Finding a framework that aligns with your rationale and objectives will be critical and will help to anchor the solution as you create it. Remember that as your work grows, your needs will evolve, and it is okay to seek out different frameworks for different purposes.



What perspective can partners bring?

• Working with people from similar and different sectors is important in creating holistic transition solutions (see Collaboration section). In working together, it is important to think about the different perspectives people can bring, including knowledge of frameworks. Ask those you are working with about frameworks they have used and found most helpful.









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How many frameworks are needed?

- Take stock of the different types of frameworks available. Depending on your work, it might make sense to use one framework or multiple frameworks. If you find multiple frameworks that could be valuable for your work, compare and contrast them to see how they may be applied together or why one might be more useful at this particular time. Ask yourself:
 - What elements of the frameworks are the same or overlap?
 - What elements of the frameworks are different?
 - Can the different frameworks be brought together to help achieve the goal of the solution? What would this look like?
 - Will some frameworks be seen as more credible than others in my sector?



What elements do frameworks offer?

- Consider the elements that frameworks have to offer to amplify the solution you are creating. Think about frameworks used:
 - In different sectors or regions (e.g., education, employment, program design, community services).
 - With different priorities (e.g., transition, collaboration, program design).
 - By different groups (e.g., race, culture, gender, socioeconomic status, disability), and what elements they have to offer to amplify the solution you are creating.





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Exploring frameworks

Throughout our work, our team has used a variety of frameworks to inform our practice. Here are four frameworks that have influenced our work (see Table 2). Please note this list presents an example of what was helpful to us, primarily from a healthcare lens, and is not exhaustive; we do not endorse one framework over another.

Table 2. A quick reference guide to possible frameworks that can help inform transition solutions

Framework

The F-Words for Child **Development**

(Rosenbaum & Gorter, 2012; CanChild, n.d.)

Offers a broad, yet simple set of foundational concepts to drive pediatric rehabilitation interactions

Description

About:

This rehabilitation framework, grounded in the World Health Organization's International Classification of Functioning, Disability and Health (ICF), packages a set of ideas into "F-words" in child neurodisability: function, family, fitness, fun, friends, and future.

Value:

- Provides a holistic and strengths-based approach, going beyond "biomedical impairment"
- Identifies "future" as central across the entire pediatric lifespan
- Positions concepts of "fun" and "friends" as essential elements of personhood and of equal importance to the other F-words

Taxonomy for Transition Programming 2.0

(Kohler et al., 2016)

Offers practical, easy to use strategies and recommendations to facilitate holistic transitions to adult life

About:

This education-based framework focuses on fostering successful transition of youth with disabilities to college and careers. Five primary practice categories are explored: student-focused planning, student development, interagency collaboration, family engagement, and program structure.

Value:

- Highlights inter-agency planning and includes information on the involvement of the adult sector prior to transition out-of-school
- Offers insights into how other complex systems (e.g., education, postsecondary, and employment) have collaborated to facilitate transitions



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Table 2. (continued)

A quick reference guide to possible frameworks that can help inform transition solutions

Framework

Guideposts for Success 2.0 A Framework for **Successful Youth Transition** to Adulthood

(National Collaborative on Workforce and Disability for Youth, 2019)

Offers practical, in-depth steps and approaches to inform holistic solutions for transitions to adult life

Description

About:

This disability-based framework outlines what all youth need to transition to adult life based on the following categories:

- School-based preparatory experiences
- Career preparation and work-based learning experiences
- Youth development and leadership
- Connecting activities (e.g., healthcare services, basic needs, life skills, financial literary, recreational and leisure activities)
- Family engagement

Value:

- Integrates best practice evidence
- Demonstrates flexibility in how the focus-areas can be applied based on context, needs, and goals
- Inclusive design for all youth as they journey to adulthood with additional supports and considerations for youth with disabilities

Transactional Framework for Pediatric Rehabilitation

(King et al., 2018)

Offers a deep dive into foundational concepts about the interplay of key processes for conceptualizing pediatric rehabilitation

About:

This transactional framework helps people consider how individuals with disabilities and their contexts mutually influence one another in ways that evolve and adapt over the life course. As youth move towards and through adult life, three pediatric transactional processes (facilitating capacity, resiliency, and socialization) are key.

Value:

- Highlights resiliency processes to support an individual's self-efficacy, self-determination, and autonomy, as well as socialization in taking on new life roles in transition
- Encourages building capacity of youth with disabilities by viewing individual situations through a lens of opportunities and experiences to create solutions that consider the context





Frameworks from other sectors



Different sectors (e.g., healthcare, community, education, and social services) have evidence, resources, frameworks, and tools suited to their unique context.

Here are some resources from other sectors that may be of interest:

- Government of Ontario: Accessible Transitions for Students with Disabilities in Kindergarten to Grade 12 (K-12)
- Council of Ministries of Education Canada: CMEC Reference Framework for Successful Student Transitions
- Ministry of Community and Social Services and Ministry of Children and Youth Services: Provincial Transition Planning Framework
- Journal Article: Planning successful transitions from school to adult roles for youth with disabilities (King et al., 2005)



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What is a solution-focused approach?

This guide comes at a time when healthcare models and service providers have collectively recognized the power and practicality of strengths-based and solution-focused perspectives to services (King et al., 2019). Solution-focused approaches are a model of communication that elicits an individuals' innate wholeness, strengths, and resources. It is driven by the child, youth, or family and it is collaborative. Adopting a solution-focused approach can:

- Improve children, youth, and family-centered supports and services.
- Promote better communication between children, youth, and families, as well as among team members.
- Increase creativity and collective solution-finding within collaborative teams.
- Facilitate better transitions to adult services for children, youth, and families by shifting the service providers' role from "expert problem-solver to facilitators of change" (Seko et al., 2021, p. 348).

But what does this really mean and how can it be introduced into daily practice?

One way to bring this approach to life is by using solution-focused coaching (SFC), where children, youth, and families focus on "strengths, desired futures, and knowledge to generate [practical] solutions to their real-life issues" (King et al., 2019, p. 16). Practically speaking, SFC uses specific words and open-ended questions to help children, youth, and families identify their own hopes for services and co-construct meaningful, individualized, and realistic goals and plans, with the provider leading them from behind. This approach leads to enhanced engagement in interventions and incremental goal achievement (Seko et al., 2021).

What does it means to lead from behind?



Service providers are often trained to fix problems for children, youth, and families in ways that may not recognize the strengths that they already have to govern and manage their needs and care.

Moving from a "leading (or fixing)" to a "leading from behind" mindset creates a collaborative environment where the child/youth and family are equal participants in their care and it is not the provider's job to fix the child/youth (because they are not broken) (Cook, 2019a).

Leading mindset

- Child/youth is problem to be fixed
- Service provider is expert
- Child/youth and family are dependent on this expertise
- Authoritative care delivery
- Emphasis on what is broken

Leading from behind mindset

- Child/youth is whole
- Child/youth and family are the expert of their lived experience
- Child/youth and family can govern their care
- Collaborative care







Using solution-focused communication in transitions

For children and youth with disabilities, one thing is certain: they will face many transitions – big and small – on the way to their transition out of pediatric services into adult systems. The role of service providers, organizations, and system leaders is to support children, youth, and their families to prepare for these transitions from a holistic or whole-person perspective, thus supporting them to thrive in their everyday lives.

With SFC, the child or youth, and family are acknowledged as the expert of their own lived experiences and the service provider is recognized as an expert in their discipline. Both types of expertise are equally valued. Children, youth, and families are supported to reflect on:

- What they want (rather than what they do not want).
- What has worked or is already working (rather than what is not working).
- What they can do (rather than what they cannot do).
- What ideas they already have for how to make things better.

For transitions specifically, this can shift ways of thinking by providing opportunities and experiences to (King et al., 2019; Seko et al., 2021):

- Cultivate resilience.
- Increase readiness and adaptability to address life changes and challenges.
- Build capacity to navigate health, education, employment, and social systems.
- Enhance self-advocacy, decision making, organizational skills, and independence, when possible.

It is worthwhile to note that for some children, youth, and families, SFC questions may sound odd. Additionally, offering language interpretation and culturally responsive supports for families who are multilingual are key, and this may take more time to work through with families (Seko et al., 2021).



Highlighting a solution-focused approach

Here are some Holland Bloorview resources to support your work:

- Fostering Positive Weight Related Conversations
- School First: Enabling Successful Return-to-School for Canadian Youth Following a Concussion
- Interview with a Humanistic Healthcare Expert: Elaine Cook



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Using solution-focused coaching in a work environment

SFC can also be used with peers in a work environment. We can (King et al., 2022):

- Shift language so our teams are more inclined to explore solutions as opposed to problem exploration.
- Change team and/or partnership processes to reflect what we want, instead of what we do not want.
- Build on what is already working for us, and work towards improving how our team functions.

Check out Appendix A for SFC tools to use in practice.



Learn more about solution-focused coaching at Holland Bloorview

An accredited team of solution-focused healthcare coaches and facilitators host workshops and accredited certifications through our Holland Bloorview Humanistic Health Care Education and Training Center. Please visit our HB Humanistic Health Care website to learn more.







What is human-centered design?

Human-centered design is an evidence-based, collaborative, and person-centered approach to addressing complex challenges or problems with the goal of creating innovative solutions that are based in empathy (Sandholdt et al., 2020).

Using human-centered design in transition solutions

Our team was motivated to use human-centered design to address gaps in services and experiences, such as feeling constrained with current resources, or frustrated with a lack of agency and processes.

This technique offers leaders and teams a flexible, yet organized approach to taking actionable and practical steps to considering the transition journey as perceived/experienced by different stakeholders and their complex contexts (Fortune et al., 2022). Much like transition experiences, the human-centered design process can get messy, emotional, and frustrating at times for participating stakeholders. However, these feelings can be transformational in creating transition solutions that capture the complex values, needs, and preferences of those involved in the transition process (e.g., children, youth, families, service providers, organizations, system leaders, funders, decision-makers).

We chose a process that embraces "messiness" rather than trying to immediately create order. We integrated the authentic, sometimes disorganized experiences of transition from different stakeholders into meaningful practices, programs, services, and suggestions that move children, youth, and families toward transitions. Beyond informing transition solutions, you can use human-centered design to bring together complex input from multiple perspectives to create change in organizational processes, services, and philosophies across any sector.



Learning about human-centered design

Here are some websites and resources about human-centered design that you might find helpful:

- IDEO.org
- Design Thinking Bootleg











Stages of human-centered design

Carrying out human-centered design requires time and planning, and may be best conducted at and/or supported by leaders within an organization as opposed to individual service providers who may already be carrying a caseload. There are five key stages to help you and the people you are working with give voice to what individuals would like and turn it into an innovative, realistic solution (Bene & McNeilly, 2020; Sandholdt et al., 2020):

STAGE 1

Sharing and understanding the lived experiences of the people with whom you are designing a solution (Empathizing).

STAGE 2

Identifying shared priorities and hopes for the future (Defining).

STAGE 3

Co-constructing knowledge and generating ideas (Ideating).

STAGE 4

Transforming knowledge and ideas into prototype solutions (Prototyping).

STAGE 5

Sharing what you have made with the people you are designing for and trying out the solution in the real world (Testing).



As you progress through these steps, it is important to integrate and evaluate the evolving solution you are working towards. Check out Appendix B for tips on how to get ready for and carry out an iterative human-centered design process.





What is collaboration?

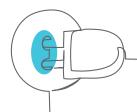
Collaboration is "an integration of activities and knowledge that requires a partnership of shared authority and responsibility" (Morley & Cashell, 2017, p. 208). Four critical elements represent behaviours and attitudes that, together, constitute collaborative practice (Morley & Cashell, 2017):

- Coordination (working to achieve shared goals)
- Cooperation (contributing to the team, understanding and valuing the contributions of other team members)
- Shared decision-making (relying on negotiation, communication, openness, trust, and a respectful power balance)
- Partnerships (open, respectful relationships cultivated over time in which all members work equitably together)

Using collaboration in transition solutions

In your context, you can collaborate with agencies, individual service providers (e.g., primary care), children, youth, and their families. There can be different levels of collaboration in a project (Prevention Collaboration in Action, n.d.). For example, low resource and/or passive approaches could include gathering feedback on a new program from children, youth, and families. Active approaches are likely to require more resources and early involvement, and could involve co-designing and co-implementing a program in partnership with other agencies and/or children, youth, and families. In particular, attend to the specific barriers and needs of children, youth, families, providers, and leaders from diverse backgrounds to encourage their participation in solution development in meaningful ways. Research suggests that collaboration can be encouraged by providing (Morley & Cashell, 2017; King et al., 2022):

- Physical and structural opportunities (e.g., group process, scheduling, organized activities, and communication tools [virtual and in-person]).
- A psychologically supportive environment.
- Appropriate education and training.







A SPOTLIGHT ON **COLLABORATIONS IN ACTION**

Impacting transition solutions through structural supports: A steering committee

From 2017 to 2022, a steering committee, which is a structural collaborative support, was created to guide our five year Transitions Strategy to improve the experience of children, youth, and families. The committee was co-chaired by an internal family leader and a staff leader. They brought together hospital staff, other family and youth leaders, and community partners (e.g., adult healthcare and community service providers) as agents of change. We needed all members (internal and external) to be actively engaged in stewarding this work to realize a shared mission of transforming practice.

In many ways, the committee acted as a community of practice with a steering mandate. Meetings focused on exploring how ongoing ideas, projects, and outcomes would both measurably and potentially change how transitions to adult life are supported. Internal and external members or groups were invited to present ongoing work in order to receive insight and feedback from the diverse group. Each member brought their practical and lived knowledge forward to consider and question how proposed or in-progress initiatives would lead to more meaningful transitions and transition preparation that aligned with the realities of the adult care and social service systems.

Our processes emphasized communication and cooperation to foster a shared responsibility in laying the groundwork to build something better, by strengthening connections among stakeholders and across sectors.



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Working with partners external to your organization can help to better address complex problems, maximize talents and assets across groups, and reduce duplication of processes and services (ASPHN, n.d.). "Collaboration between partners can range from informal (e.g., two agencies sharing information) to much more organized (e.g., multiple agencies working closely to achieve a shared vision)" (Prevention Collaboration in Action, n.d., p.1).

Working with partners in transition solutions

Throughout their lives, children, youth, and families navigate the complex network of transition services that are often in silos within health, community, education, and social contexts. As service providers, organizations, and system leaders, we want to deliver solutions that are effective and integrated to meet the desired and culturally relevant needs of children and families within our systems.

Working with partners outside of your organization, either within the same or a different context, can support this aim by shifting the ways that we approach transition service delivery. Engaging in this process is effortful and takes time (even years) to achieve change, with many aspects of the system remaining outside of our control (i.e., funding, system structures, management, and leadership support). Some efforts may see guick wins but other initiatives might feel like a marathon. As a point of reference, our Transitions Strategy Team has been working for 20 years towards the goals set out in this guide, including securing dedicated funding and building the necessary community partnerships.

Over the past five years, our team has worked to address complexities of transitions by collaborating with groups that provide similar services. We have shifted our mindset to work towards solutions that address deeper issues affecting transition experiences within our sphere of influence. We have recognized that we can leverage our connections, and can reach out to others in the system to start a conversation and explore possibilities. Initial connections do not need to result in a coordinated or co-developed initiative. It can be as simple as sharing the successes and challenges of our similar experiences. Ideas grow from mutual interest, strengths, resources, and support.

Partner collaboration



Here are some resources you might find helpful:

- Prevention Collaboration in Action: Understanding the Basics
- Association of State Public Health Nutritionists (ASPHN) Collaboration Primer
- Journal Article: Applying an ecological framework to understand transition pathways to post-secondary education for youth with physical disabilities (Lindsay et al., 2018)





Reflect on where you are already doing collaborative work

Chances are, you are already doing collaborative work. Here are a few things you can ask yourself to start your thinking about working with partners. Take some time to answer the following:



What are you already doing? Who are you already partnered with (formally, informally, casual connections)? What resources do you currently have (resources can be financial, material, time, human)?



What is working well? What difference is it making? Who is noticing the work you are doing and in what ways?







Given what is working, how might you either expand current partnerships and/or seek out new partnerships to further transitions supports for and experiences of children, youth, and families across multiple agencies?



Can you shift where, how and/or who you work with so that the existing resources (e.g., funding, workload) across partners is complementary and can have a greater impact for children, youth, and families?



Within the partnership work, how might you further build structures for joint accountability in transitions to adult services?



What real world difference does/can these authentic partnerships make for children, youth, and families, the organizations involved, and the system?

Considerations for starting to work with new partners

You can engage with partners outside your organization by:

- Reaching out to aligning agencies (e.g., similar work, goals, population, vision for equitable service delivery) or those that could be a good fit to work with.
 - Start with an agency you are familiar with, have a history of referrals, or one you have worked with before.
 - Try "cold calling" staff at new agencies or forming connections at forums (e.g., conferences) to meet potential partners. Collaboration can emerge through repeated interactions.
- Referring children and youth to their existing program, co-delivering a program that has already been developed, and/or creating a new program together.





As you begin to formalize your collaboration, we have found that partnerships are strengthened when some or all of the following things are in place:



Leadership support

• Senior management or leadership commitment, support, and participation in the interagency collaboration is essential. This may be realized by committing to and valuing the larger process of creating relationships and partnerships across agencies, instead of a single end goal, and supporting a two-way distribution of power (top down/bottom up and vice versa).



Alignment

• Be open to possibilities and try not to hold preconceived notions of your alignment before meeting with an agency. Finding some commonalities can be enough to create shifts in culture so that assumptions and beliefs become more aligned over time.



Commitment and resources

- Participating agencies need to have equitable commitment to resourcing and undertaking program processes and implementation. It is important that one agency does not feel burdened by the other.
- Equitable commitment may not be 50/50. It depends on partnership needs for success and available resources. Outlining responsibilities for each group member as part of resource planning is helpful.
- Decide with your team what internal resources can be formally allocated to support the collaboration (e.g., staff time, funding). When projects are 'side of the desk', they may become unsustainable over time.



A plan

- Establish a clear and shared vision, goals, and terms of reference for the collaboration. As you create your plan, include time for systematic reflection, learning, evaluation, and flexibility along the way.
- Visual tools (e.g., logic models) help communicate goals, activities, resources, outputs, and intended outcomes. Mapping out these aspects together can bring assumption to light and offers a strengths-based approach to build trusting relationships between agencies.



Information sharing

• Ensure all partners have easy and equitable access to collaboration materials. Try using cloud-based mechanisms for sharing non-confidential information across agencies (e.g., Dropbox, Google Drive, MS Teams).





A SPOTLIGHT ON **COLLABORATIONS IN ACTION**

Student led environments support transition navigation through a unique partnership

The OnTrack program is a collaboration between Holland Bloorview and the Centre for Advancing Collaborative Healthcare & Education (CACHE) at the University of Toronto. OnTrack is a cluster of Student Led Environments (SLEs) which provide unique workplace-based learning opportunities for health professional learners (CACHE, 2022). OnTrack works with what we already have (students to be supervised, knowledge of processes that work for transitions) to amplify outcomes for children, youth, families, organizations, and our system. It acts as a designated pathway for future practitioners that share our ethos of solution-focused, collaborative, innovative, and evidence-informed care.

Within the Transition Strategy, we have integrated the OnTrack Transition SLE into our Transitions Pop-Ups (see example 3). When children, youth, and families attend a Transitions Pop-Up on a topic of interest to them (e.g., legal considerations for the transition to adulthood), they are connected with a service provider student on placement at Holland Bloorview. The student provides focused, practical, and individualized coaching related to the topic of interest, and supports children and youth in planning and navigating next steps as they prepare for the transition to adult life. The pairing is meant to be one of equals, with the child/youth as an emerging expert in their own needs related to transition to adult life, and the student as an emerging expert in service provision related to transitions.

The students receive training in leadership skills, use a solution-focused approach, apply transition and pediatric frameworks, and provide child-, youth-, and familycentered care. The students meet as a group with interdisciplinary preceptors to debrief their coaching sessions, furthering their interprofessional learning.

Under the supervision and support of preceptors, facilitators, and Family as Faculty, the SLE offers students leadership skills at multiple system levels, such as supporting children and youth to achieve individual goals, and developing internal systems to address gaps in transition work more broadly. Due to the coaching nature of an SLE, the organization benefits as preceptors are able to take on more students to reach more children and youth.

Overall, students studying nursing, occupational therapy, social work and therapeutic recreation have participated in the design, development, and delivery of services.

The OnTrack Transition SLE is one of several at Holland Bloorview. Read more about SLEs on the CACHE SLE website.



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द्वे Working with children, youth, and families

Children, youth, and families know best what it is like to live their own lives. They bring expertise based on their firsthand experiences of navigating challenges, managing their needs, receiving services, and providing support to a loved one (Vojtila et al., 2021). Their lived experience includes their disability as part of their multiple identities as a whole person. Parents, siblings, grandparents, guardians, and other caregivers can amplify the voice of children and youth, and share the experiences of children and youth who are unable to easily voice their own lived experiences.

These lived experiences are not static and will change at different points in a child's or youth's journey from childhood to adult life. Children and youth voices can help create solutions that reflect the many different types of transition. Transition experiences are also personal and unique to an individual; representation of diverse experiences matters.

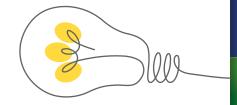
Embracing children, youth, and families as change agents in designing transition solutions is a necessity. Such an approach amplifies their expert voices, and shakes up what has already been tried to realize meaningful system change. Involving individuals with lived experience as partners early on in solution design helps address immediate needs and impacts outcomes for future children and youth (Vojtila et al., 2021).

Establishing Patient and Family Advisory Committees: The Patients First Act (Bill 41) as a resource



Bill 41 - Patients First Act, 2016, was created to amend various Acts in the Province of Ontario in the interests of patient-centered care. Patient and Family Advisory Committees to discuss matters related to clinical care, service delivery, and quality improvement are featured prominently in this Act.

This legislation is an example of system policy development. Organizations can use Bill 41 to establish mechanisms for increasing child, youth, and family engagement to improve care.







Asking children, youth, and families what has worked, what has not worked, and what will most benefit others like them will help create solutions that are grounded in the real-world complexity of navigating transition to adult life and adult systems. As a service provider, organization or system leader, you can drive children, youth, and family engagement and partnership to improve service experiences and inform different levels of the system, including (Carman et al., 2013):

- Service delivery (e.g., co-design new solutions, improve existing solutions).
- Organizational design and governance (e.g., plan, deliver, evaluate services).
- Policy development (e.g., plan, implement, and evaluate programs, standards, and policies).

Select the right term(s) for your organization

There are many terms that can be used to explain children, youth, and family participation. Terms you may come across are:

- Engagement
- Shared decision-making
- Partnership
- Child-, youth-, and family-centered care
- Collaboration
- Patient partnered care

Review the literature to help you understand these terms and choose one(s) that are the best fit now or as aspirations to work towards.

Understanding what we mean by engagement and partnership

Engagement invites meaningful and active participation from children, youth, and families to shape the service experience around their needs and preferences (Carman et al., 2013; Higgins et al., 2017).

Partnership refers to an open and authentic relationship (established over time), where two or more actors (e.g., individuals, groups, organizations) work together towards a common goal or outcome (Huang et al., 2018; Morley & Cashell, 2017).



Our transition strategy efforts have focused on service delivery, and organizational design and governance. To help us with our strategy, we have and continue to engage children, youth, and families along a continuum of approaches, ranging from passive consultation to active partnership and full shared leadership (Carman et al., 2013).

In your work, consider including child, youth, and family perspectives at the earliest point possible in solution design. Know that their engagement is an iterative process. Embracing an engagement continuum also means that there are many entry points along the way. See <u>Table 3</u> for an example of a continuum for engaging children, youth, and families in organizational design and governance.



Table 3. A continuum for engaging clients and families in organizational design and governance

Types of engagement	Description of types of engagement	Examples of engagement in action
Consultation (Carman et al., 2013)	Gathering feedback from children, youth, and families who use your organization's services, about their experiences at a single point in time	 Engaging children, youth, and families in planned events (e.g., journey mapping exercise, feedback sharing discussion) Surveying child, youth, and family service users on their transition preparedness (e.g., email survey, onsite survey)
Involvement (Carman et al., 2013)	Children, youth, and families are involved as advisors and are part of organizational structures (e.g., advisory council, committee members) sustained over time	 Child, youth, and family partners as standing committee members, with equal voice in advancing committee goals (e.g., representing service-user and lived experience as a member of the transitions strategy steering committee)
Partnership and shared leadership (Carman et al., 2013)	Children, youth, and families co-lead organizational committees and initiatives	 Child, youth, and family partners involved in co-design and co- facilitation of engagement activities, ensuring equal participation from all individuals (e.g., family member as co-chair of the transition strategy steering committee)
Lived experience family educators (Referred to as Family as Faculty at Holland Bloorview [Holland Bloorview Kids Rehabilitation Hospital, n.d.])	Family partners who have completed training to teach and facilitate, drawing on their lived experience; family partners as Faculty receive an honorarium in recognition of their valued contribution to education and training of staff, students, and other families	 Co-teaching and facilitating transition events (e.g., Family as Faculty co-designing and co-facilitating transitions <u>Pop-Ups</u> and <u>webinars</u>)
Lived experience employees (Seko et al., 2022)	An individual with lived experience who supports youth and their families by sharing personal experiences and is a paid member of the team	 Meeting with children, youth, and families in a service setting to support them with creating transition plans and goals Young adults as <u>Youth Facilitators</u> leveraging their own lived experience of transition to share tips for



navigating adult services and life

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Up to this point, we have talked about the importance of working with children, youth, and families, and how they utilize their lived experience across a continuum of engagement. We have also shared some tangible examples on how this can be achieved.

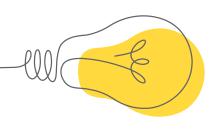
It is important to remember that when children, youth, and families engage in the work we do, they are giving their time and energy, which may already be limited, to a cause that they are passionate about. We need to be mindful of their ability to engage in the work (whether, when, and how they participate) and consider factors that might impact their engagement. While there are many factors that might impact engagement, here are a few to consider as you work with children, youth, and families:

Personal factors (Carman et al., 2013)

- Believing that children, youth, and family engagement is essential and has real impact on service, program, intervention, resource, process, and tool development and delivery
- Seeing that they can contribute based on their own experiences
- Feeling confident that their experience, feedback, and ideas will be used to help improve the experience of others and affect change (Micsinszki et al., 2022)
- Capacity to participate (e.g., health literacy, health status, time, competing responsibilities, geographical location, desire to contribute)

Organizational factors (Carman et al., 2013)

- Senior leadership support for building a culture that fosters authentic engagement and partnership
- Dedicated funding to support a formal engagement and partnership strategy
- Creating and implementing policies or practices that may impact levels of engagement or partnership and ease of working with children, youth, and families (e.g., process for requesting children, youth, and families to participate on projects/committees, guidance for staff on how to effectively partner with children, youth, and families)
- Valuing contributions of child, youth, and family partners with tangible and meaningful rewards (e.g., honorarium, gift, volunteer hours)
- Removing barriers to participation (e.g., timing of meetings or events, funding transportation/parking, attendant care or childcare, access to technology, translation services)









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Societal factors (Carman et al., 2013)

- Perception of belonging to a community and recognition of the value of contributing to improved supports, services, programs for all
- Genuine belief that child, youth, and family contributions will be meaningful, and that the time and energy they invest through engagement and partnership opportunities will have an impact
- Mechanisms and opportunities to provide input and inform organizational policies and procedures that meet child, youth, and family needs (e.g., informal feedback sessions and town hall meetings instead of membership on committees)

Enabling child, youth, and family engagement and partnership in designing transition solutions

In our experience, capturing the voices of children, youth, and families works well for designing transitions solutions when:

- Engagement is sought at the onset of the work and children, youth, and families are involved in activities (e.g., creating, designing, planning) from the beginning.
- A clear vision for participation has been identified (see the <u>examples</u> for illustrations of child, youth, and family engagement and co-design).
- Level of commitment and roles and responsibilities are co-established early on.



- Expectations and resources align with the level of engagement (e.g., meeting frequency, compensation).
- Diverse experiences are sought (e.g., age, type of disability, gender identity, race, ethnicity, socioeconomic status, sexual orientation, religion, geographic location).

Having structures and processes for child, youth, and family engagement and partnership built-in at the organizational level is not limited to transition solutions and can make engagement work for any program more accessible. Here are some helpful websites and resources:

- Health Quality Ontario Patient Engagement Framework
- Health Quality Ontario Patient Partnering Tools and Resources: Building Equity and Diversity Into Your Engagement Activities
- International Association for Public Participation: IAP2 Spectrum of Public Participation
- Journal Article: Codesigning simulations and analyzing the process to ascertain principles of authentic and meaningful research engagement in childhood disability research (Micsinszki et al., 2022)





A SPOTLIGHT ON **COLLABORATIONS IN ACTION**

Holland Bloorview's youth engagement strategy

Our youth engagement strategy enables current and former Holland Bloorview youth to turn their lived experience into change for future generations. Consider how this strategy aligns with or could bolster your organization's efforts to design transition solutions.

Our youth engagement strategy involves engaging youth in the following ways:

- Youth Advisory Council (volunteer activities)
 - Consult on research and strategic initiatives (e.g., transition programs and services)
 - Act as a sounding board for the hospital community (e.g., provides a youth voice where strategic level decisions are being made)
- Youth Mentorship Program (volunteer activities)
 - Youth mentors participate in training to prepare them to:
 - Provide cross-age/disability mentoring that is tailored to youth needs and wants (e.g., building a relationship with a new adult healthcare team).
 - Act as educators to the healthcare community (e.g., sharing their reflections) about the services and preparation for transitions they received).
- <u>Lived Experience Employees</u> (paid roles)
 - Clinical roles
 - Youth Facilitators at Holland Bloorview (Seko et al., 2022) meet with youth and families as part of the clinical team to support their preparation for transition to adulthood
 - Non-clinical roles
 - Strategically embedded throughout the organization to leverage lived experience in meaningful ways (e.g., inpatient teen lounge is staffed by a youth with experience receiving hospital services)



Tenets in action: A spotlight on transition solutions at Holland Bloorview

The goal of Holland Bloorview's Transitions Strategy is to generate a suite of holistic solutions to improve transition experiences of children and youth with disabilities and medical complexity. Areas of focus include medical transfer, post-secondary education, employment, living options, and community participation.

In this section of the guide, you will find four examples of the innovative transition solutions that emerged. This is not an exhaustive list of the solutions we have put in place but provides a starting point to inspire you.

By sharing these examples we aim to:

- Demonstrate the tenets in action, and how they facilitate the transformation of practice.
- Connect solutions to different organization, service provider, system leader, child, youth, and family needs and describe our processes.
- Stimulate your thinking about how you can apply the tenets to create transition solutions within your own context.





We hope this guide will inspire you!

After reading this guide learn more about our processes and the work of the Holland Bloorview Transitions Strategy Team:

Journal Article: A case study of a strategic initiative in pediatric rehabilitation transition services: An insiders' perspective on team principles and practices (King et al., 2022).





Transition solutions at Holland Bloorview

The following four solutions were chosen to best illustrate the tenets in action:



Getting Started Early Webinars

- Provides building blocks
 (e.g., creating habits, routines) to
 prepare children, youth, and families
 for many of life's transitions
- Shares information through virtual education and lived experience connection opportunities



Employment Pathway Services

- Guides children, youth, and families towards opportunities for early and diverse volunteer and work experiences
- Assists community employers in creating more inclusive work environments



Transitions Pop-Ups

- Addresses different topics
 (e.g., life after high school, health
 and wellness) through group events
 co-hosted by Holland Bloorview, an
 adult agency, and youth and families
 with lived experience
- Creates opportunities for children, youth, and families to learn from others who have been there before



Personalized Transition Plan

- Supports children, youth, and/or families to create personalized plans, set goals, access personalized resources, and take steps toward adult life
- Functions as a self-directed, stand-alone tool that children, youth, and families can download and work on independently and/or with coaching support



Other transition solutions at Holland Bloorview

For more evidence-informed, community integrated services for children, youth, and families check out our <u>transitions</u>, <u>recreation</u>, and life skills website.



Example 1: Getting Started Early Webinars



Background

In working with families across the spectrum of life transitions (i.e., entering kindergarten through exiting high school), we discovered families had similar questions arising about "the future" regardless of age, program, or diagnosis:

- Does my child have things they like to do?
- What opportunities are available for my child?
- How can I support my child's dreams?

Tenets in action:

- Collaboration:
 - Working with partners
- Working with children, youth, and families
- Solution-focused approach



Opportunity

We realized that more information and support was needed for families at all stages of growing up and that there was an opportunity to start thinking about and planning for a meaningful life earlier on.

The Getting Started Early Webinars were developed with internal and external partners and families to foster education and connection opportunities (i.e., family to family and partners to families). The ultimate goal of this initiative was to lay the foundation for meaningful transitions early on in the family's journey.



Solution

The webinars provide virtual learning and connection opportunities for families supporting a child or youth with a disability through transitions. The webinars focus on:

- Sharing information about specific transition topics, such as practical steps, timelines, and relevant agencies and supports.
- Connecting families with others who have already been through that transition to learn what has worked and share advice.
- Connecting families with an external agency or internal service to plan next steps within the healthcare system and community.
- Fostering hopefulness in families by providing an understanding of the road ahead through resources, advice, and planning.



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About the Getting Started Early Webinars

Table 4 provides highlights of webinar topics and internal and external partners engaged. Initially, webinar topics focused only on first transitions into the healthcare system and into kindergarten. They were geared to families with children under the age of six to assist with current transitions and build the foundation for future transitions, set expectations, establish routines, and promote resiliency in the child and family.

Since then, topic areas have expanded to support children, youth, and families growing up in the healthcare system and transitioning out of high school. A focus on parent and caregiver mental health and wellbeing has also been an important addition.

Table 4. **Examples of webinar topics and partners**

Webinar Title	Partners	
	Internal	External
Transition to Kindergarten for Families with Early Learning and Development Needs	Family as FacultyEarly Learning and Development program	• N/A
Home for the Holidays (with a focus on routines)	• Family as Faculty	Centre for Inquiry CanadaToronto District School Board
"What Can I Be When I Grow Up?" Start Early for Employment Inclusion	• Family as Faculty	 Ontario Disability Employment Network
Life after High School: Start Thinking About Your Next Steps for Supported Employment and Continued Learning	Lived Experience Family Educators	• ConnectABILITY.ca

Getting Started Early Webinars: Five key actions

We take an iterative approach using five key actions to create the webinars:

ACTION 1

Gather feedback from families via surveys and focus groups to determine priority topics and themes.

ACTION 2

Identify and connect with internal and external partners based on feedback and relevance to chosen topic areas.

ACTION 3

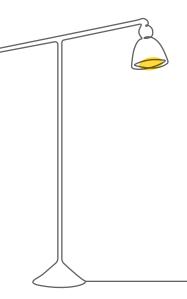
Co-develop content with identified partners, children, youth, and families.

ACTION 4

Gather post-webinar feedback from participants, and internal and external partners.

ACTION 5

Synthesize post-webinar feedback and debrief as a group to discuss and incorporate changes.





Collaborating with families to develop the content and present the material has ensured that the information is relevant, the wording is intentional, and that families are hearing directly from someone who has been through a similar experience.

It is especially impactful for families with young children who are just beginning their journey through life's transitions to hear from families with youth transitioning to adult life – who have been through what they are about to experience.

Hearing from diverse lived experience experts offers more than one path, instills hope and confidence in families, while also recognizing challenges that may lie ahead.

Working with partners in the community has enhanced the content and reach of the webinars. The webinars can be an opportunity to partner with an organization already known to families (e.g., a local school board) or introduce families to an organization they may not already be aware of (e.g., an internal or external support in the community). Including partners in the webinar development and presentation ensures that the information shared is accurate and current.



Working with children, youth, and families

A great way to involve registrants (i.e., children, youth, and families) in webinar content production is to ask questions as part of the registration process.

Try asking questions like:



- "This webinar would be helpful if _____"
- "I'm looking for information on _____"

This helps to create relevant content for the participants in that particular session. It also allows you to address specific questions and areas that participants need more information on.



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Using a solution-focused approach to develop and implement the webinars also helps to meet families' needs. This practice allows for the use of language that is meant to increase family engagement in sessions and have them leave feeling capable and hopeful.

The solution-focused elements of the webinars include:

- Finding external partners who share our solution-oriented values.
- Framing the topic in a solution-focused way.
- Introducing solution-focused language to families early on and discussing how it can be helpful in developing plans.
- Ensuring the content (e.g., scripts, resources shared) emphasizes strengths and resources.
- Using solution-focused language to describe behaviours and challenges.
- Inviting families to focus on opportunities and strengths.
- Asking solution-focused questions (leading from behind) when gathering feedback from families.

See Appendix A for solution-focused support materials.

Other important items to consider when implementing webinars include:

- Choosing a virtual platform to run the webinars (e.g., Zoom, Google Hangouts, MS Teams).
- Meeting your organization's guidelines on virtual services (e.g., standard operating procedure).
- Using methods to support and enhance security.
- Implementing accessibility features as appropriate (e.g., transcription, translation, screen reader support).
- Managing virtual privacy needs and expectations of participants.
- Planning for emergent mental health or wellness needs (e.g., crisis resources).
- Engaging the audience and encouraging appropriate participation.
- Using strategies to bring conversation back to the main topic (see Appendix A).





Impact

Prior to the COVID-19 pandemic, a few sessions were piloted as in-person events for our organization's children, youth, and families. Shifting to a virtual model allowed us to open up the registration to families outside of the organization, expanding our reach. Since the first webinar in December 2020, we have offered 20 webinars, with a combined total of over 630 attendees. The virtual model reaches a wider audience, and also keeps costs and resourcing needs low, making this solution more sustainable for the organization than the initial inperson pilot. Virtual delivery also reduces demands on a family's participation, such as transportation, travel time, and childcare.

The sessions are evaluated with a survey that is sent out to participants after each webinar. The survey includes prompts such as:

- "With this information, I will..."
- "I really liked these parts of the workshop..."
- "This session could have been better if..."



Over the course of the program, we have received meaningful feedback from webinar participants speaking to the impact of this work and action they'll take:



...I learned so much tonight to help my son fulfill his dream. Thanks for the fantastic resources. Seems a bit daunting, but you have all helped me feel calmer, knowing with research I can do this for my son."



I have a better understanding of what I should do for my daughter's well-being when she enters Kindergarten in September."



[I will] make time to envision my child doing a great deal in life."







Background

Access to employment experiences is important to the lifelong health and well-being of youth with disabilities. Early employment participation builds confidence through accomplishments, creates social engagement, and drives post-school employment success. While they are in high school, youth with disabilities often face barriers accessing relevant employment experience opportunities, such as paid work, volunteering, school co-op, or chores in the home.

Tenets in action:

- Human-centered design
- Frameworks
- Collaboration:
 - Working with partners
 - Working with children, youth, and families
- Solution-focused approach



To address this need, Holland Bloorview created an **Employment Pathway Service** to guide youth, families, and community partners towards a more inclusive and diverse workforce.

Solution

Building on existing employment participation programs, we undertook a humancentered design initiative (see Appendix B) to shape and map services that would best meet the needs of youth, families, and community partners. Activities involved:

Exploring evidence and best practice <u>frameworks</u> with a focus on youth development and employment skill building.

- Conducting interviews and surveys of past program participants.
- Reviewing outcome data from employment participation programs.
- Hosting design events with youth, families, employers, policy-makers, and members from the employment services sector (e.g., staff, agencies).

This process resulted in:

- Stronger community connections and collaboration for program delivery and research.
- Commitment of dedicated staff to facilitate community education and awareness activities.
- Structuring the individual employment participation programs into a comprehensive and progressive pathway.



About the Employment Pathway Service

Programming is available to youth, regardless of diagnosis. Youth start during high school and typically participate over a period of two to three years. The pathway moves youth progressively towards relevant employment experiences and outcomes (e.g., chores, volunteering, paid employment), with the flexibility to participate in programs in any pathway "step" that best suits their current needs (not necessarily linearly).

General features of the pathway include:

- Self-discovery, employment planning, and job coaching.
- Career preparation and supported seasonal work experiences (e.g., volunteer, co-operative education, paid employment).
- Life and employment skills training through workshops and job placements.
- Job search activities

A solution-focused approach is used in all coaching/consultation meetings and workshops. Discussions focus on questions such as:

- What does the youth want?
- What is important about their goal(s)?
- What will be different for them when they achieve the goal?
- What steps will count as progress for them?
- What is already working?
- What strengths and supports can assist them in accomplishing their goal(s)?

See Appendix A for tools to support these conversations.

Working with children, youth, and families is a critical part of this service. All Employment Pathway workshops include first-hand sharing of lived experiences. A full-time Youth Facilitator (a young adult trained to share their lived experience as someone with a disability in order to facilitate change) is a core member of the service team (Seko et al., 2022). The Youth Facilitator uses their lived experiences of transition to education and employment opportunities to engage and support youth and their families as they plan and navigate their own journeys.





Employment Pathway Service: Four key stages

The employment pathway service involves four key stages:

SELF-DISCOVERY AND EARLY SUPPORTED EXPERIENCE PROGRAMS (STAGE 1)

Youth explore the world of work and gain experience through volunteering within a structured program. Program elements include: personalizing goals in partnership with youth and their family; developing work experiences customized to youth's interests, goals and abilities; on-the-job coaching of workplace-appropriate life skills and tasks (e.g., time management, self-advocacy, decision-making); and participating in workshops and social activities led by a Youth Facilitator.

EMPLOYMENT ACTION COACHING (STAGE 2)

Youth and parents (or other caregivers) attend 3 group sessions developed and delivered by an occupational therapist and family partner with lived experience in supporting a youth with a disability to find employment (Family as Faculty). The sessions help them to learn about job search strategies, consider actionable steps towards employment participation, and connect with other youth and families. They also attend three or more one-to-one sessions with an occupational therapist to prepare job search materials and solidify their action plan for their next step of employment experience(s).

INTENSIVE SUPPORTED WORK EXPERIENCE (STAGE 3)

Youth who have previously participated in employment action coaching are supported to connect with local employers for short-term paid work experiences (summer or co-operative education). Program staff coach and support potential employers with the recruitment and job start-up phases. Staff also assist youth with job preparation (e.g., job search skills, life skills) and start-up (e.g., workplace accessibility consults, on-the-job coaching). Supports are flexible according to individual youth and employer needs.

CHECK-INS AND NEEDS-BASED CONSULTATIONS (STAGE 4)

Program graduates may reconnect if needed for consultation during their high school, post-secondary, and transition-to-work journeys. Staff assist youth and families to connect with community employment service providers for ongoing support through "warm referrals" when possible.





Impact

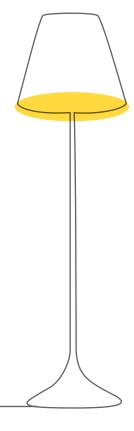
As of 2022, Holland Bloorview supports approximately 50 youth per year with their early work experiences. In addition to collecting satisfaction and goal progress data immediately post-service participation, follow-up surveys are conducted regularly and focus on outcomes within two years of participation.



Supporting employment opportunities

Here are some resources that you can use to support youth with disabilities to connect with early work opportunities:

- Holland Bloorview Employment Participation Programs
- Journal Article: The creation and implementation of an employment participation pathway model for youth with disabilities (Bowman et al., 2022)
- Holland Bloorview Employer Resource Hub
- Healthy And Productive Paid work for Youth with disabilities (HAPPY)







Illuminating voices: Youth perspective

Andrew began participating in Holland Bloorview's Employment Pathway at age 15. In the Youth@Work program, he explored his interests and strengths while volunteering during the summer (pathway stage 1). He likes reading, online learning, and roles with lots of movement that use his physical strength. He and his mom signed up for Employment Action Coaching (pathway stage 2) with a goal to get a summer job. Andrew then moved on to Intensive Supported Work Experiences (pathway stage 3). Please note that Andrew's movement through the pathway stages happened over several summers.

One of Holland Bloorview's employer partners had summer student roles in the mailroom involving data entry, mail deliveries and pick-ups, as well as stocking printers and supply rooms throughout the organization – a good match for Andrew's strengths and interests.

Holland Bloorview Employment Pathway occupational therapists supported Andrew and the employer in an adapted selection process and job start-up. Andrew shared that he does his best work when he has consistency in work routines and clear information about how he is expected to do the work. Demonstrations of procedures are also really helpful for him. On the job, coaches worked with Andrew and his mailroom co-workers during a start-up phase, gradually fading the coaching involvement over time.

The summer experience was successful for both Andrew and his employer. Andrew said, "I got more confident with my working skills and I got more social." His co-workers in the mailroom reflected, "It was a very useful experience to work with individuals who have different learning patterns and it made us all appreciate the importance of giving and receiving clear instructions, as well as being more organized in our workday."

Andrew was supported to connect to other life skills programs and post-secondary transition services, as well as youth employment organizations as he continued to work towards his goals (pathway stage 4).



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Example 3: Transitions Pop-Ups



Background

As youth with disabilities turn 18 in Ontario, there are multiple, interacting changes that occur based on current funding models and legislation. This includes the transition to adult healthcare, social care, and funding. Youth, families, and service providers all reported the need for more personalized, holistic support for the transition to adult life.

Creating a new service delivery approach for the transition to adult systems would improve the experiences of children, youth, families, organization, and service providers alike. Focusing on access to services, funds, environments, and skills to overcome barriers to full participation in adult life with a disability is deemed essential (Thompson et al., 2023).



The <u>Transitions Pop-Ups</u> (<u>Pop-Ups</u>) were developed as an approach to service delivery that facilitates more actionable and meaningful transitions to adult life. This approach was created for Holland Bloorview children and youth ages 14 years and older as they move towards graduating from pediatric services.

Solution

How do we transform the experience of transition to adult services? This overarching question guided a two-year <u>human-centered design</u> process (see <u>Appendix B</u>) to create a cultural shift in the way we think about transitions (King et al., 2022).

The work was supported by the Ontario Ministry of Health Business Innovation Office. It was completed in partnership with 30 Holland Bloorview Youth and Family Leaders (youth and families with lived experience), 27 Holland Bloorview staff, and 32 community partners from adult and pediatric sectors to standardize and personalize a new way to deliver these crucial services. Through the empathy-building process of human-centered design, these groups decided that the co-designed solution would be most effective when it is simple in its delivery, able to address a wide range of topics, and adaptable to individual children, youth, and families.

This is how the Pop-Ups model was born.

Tenets in action:

- Human-centered design
- Collaboration:
 - Working with partners
- Working with children, youth, and families
- Solution-focused approach



About the Pop-Ups model

Pop-Ups are topic-based group events for children and youth 14 years and older and their families. They are co-designed and delivered with a Holland Bloorview staff, adult community partner, OnTrack Transition SLE student(s), and child/youth, or a family member with lived experience (see <u>Table 5</u>). They can be held virtually, hybrid, or in-person. Where possible, in-person events are held at the partner agency to increase the child, youth, and family's contact with new environments.

We have a variety of internal and external partnerships to support our Pop-Ups:

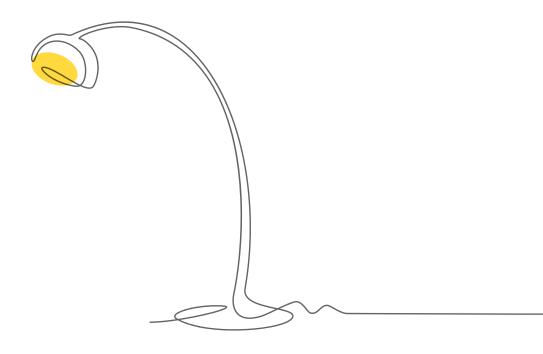
Table 5. Internal and external partnerships

Holland Bloorview departmental partners (internal)

- Client and Family Integrated Care
- Family Leadership Program and Family as Faculty
- Health Information Management
- Youth Mentors from the Youth Engagement Strategy

Organizational partners (external)

- Ontario Disability Support Program
 - Developmental Services Ontario
 - Pro Bono Ontario
 - Yorktown Family Services
- Vibrant Healthcare
- Extend-A-Family
- ConnectABILITY.ca
- Centre for Independent Living Toronto
- March of Dimes Canada

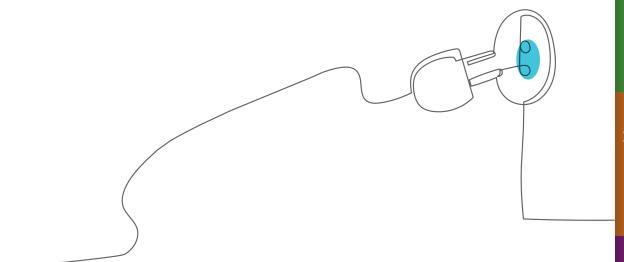




(III)

Pop-Ups help to gradually bridge the family's journey towards adult life, going beyond traditional service offerings by:

- Using a <u>solution-focused approach</u> (see <u>Appendix A</u>) to gather children, youth, and family attendees' best hopes in advance, giving us the ability to tailor the event.
- Using multi-modal education techniques such as brief presentations, experiential learning, sharing lived experiences, and group and one-to-one interactions for optimal learning.



Pop-Ups topics

Pop-Ups explore a variety of topics including:

- General introduction to transitions
- Financial and legal
- Health and wellness
- Personal care
- Life after high school
- Mentorship and peer connections
- Staying organized and on track
- Sexuality and disability

Visit Holland Bloorview's Transitions Pop-Ups website to stay up to date on current topics.









Pop-Ups: Five core elements

Pop-Up sessions are always grounded in five core elements:

COMMUNITY PARTNERSHIPS (ELEMENT 1)

Events are co-designed and co-hosted by Holland Bloorview and one or more adult-sector agencies. This creates earlier exposures to new service environments for our children, youth, and families. It also gives agency partners the chance to meet, understand the needs of, and recruit future participants for their programs or services.

INFORMATION SHARING (ELEMENT 2)

Sharing information about the Pop-Up topic is a key part of the session. It is paired with creating a safe space for diversity and inclusion. It is important that participants ask questions and have discussions with session co-leads and participants.

PEER MENTORING (ELEMENT 3)

Pop-Ups are co-facilitated by a youth and/or family member with lived experience. Hearing from someone with lived experience creates a welcoming atmosphere and encourages openness and trust with attendees. Co-facilitation helps to reduce power imbalances.

ACTION (ELEMENT 4)

Pop-Ups are geared towards "checking something off the to-do list" and incorporating the completion of a task related to the topic. For example, for Pop-Ups that run in partnership with the Ontario Disability Support Program (ODSP), children and youth who are eligible for income support and benefits from the ODSP complete and submit an application form during the event.

WARM HANDOVER (ELEMENT 5)

Pop-Ups initiate interactions between adult-sector agencies and the children, youth, and families who may be accessing their services in the not-so-distant future. These interactions help to build relationships and can translate into real-time and warm referrals, reducing the chance of lost referrals. This is an important feature of the Pop-Ups model.





Impact

Our Transitions Pop-Ups are recognized by Accreditation Canada as a Leading Practice.

In 2022, Holland Bloorview co-hosted 70 Pop-Up events, servicing 433 children, youth, and/or family members. Based on an initial evaluation, we expanded the variety of Pop-Up topics and increased the number of adult agency partnerships. We continue to administer post-event evaluation surveys to gather feedback to help improve the Pop-Ups for future participants.

In light of potential shifts in funding and program resourcing, we used a solution-focused lens to consider the resources that we already had available to us to achieve our goal of sustaining and expanding the Pop-Ups. Integrating the Pop-Ups with ongoing student placements was identified as a viable solution to sustain the resource while providing training through the OnTrack Transition SLE. Students offer focused, practical, and individualized coaching related to Pop-Up topics. They support children and youth in planning and navigating next steps as they prepare for the transition to adult life. Benefits of integrating students into the Pop-Ups model include rich learning experiences for the next generation of practitioners, increased financial sustainability of the model, and helping to maintain staffing ratios at a level that allows for group and individual attention.

Looking ahead, the hope is to expand the Pop-Ups model provincially, nationally, and internationally to create better transitions to adult life for children, youth, and their families (Thompson et al., 2023).

Pop-Up Model



Read this article to learn more about Holland Bloorview's Pop-Ups model

- Health Standards Organization Leading Practice Library: Transition Pop-Ups - Transforming Healthcare through Design Thinking Methodology
- Journal Article: The Transitions Pop-Ups Model: Transforming the journey to adulthood for youth with disabilities and families (Thompson et al., 2023)











From the start of the human-centered design process, staff members from March of Dimes Canada (MODC) have been part of the journey to create the Pop-Ups in partnership with Holland Bloorview.

Both organizations share values and goals to support people living with disabilities to have meaningful transitions through programs that encourage growth and development. MODC programs and services typically support older age groups than Holland Bloorview, making them a great "warm handover" partner for the Pop-Ups.

One such MODC program, Learning Independence for Future Empowerment (L.I.F.E.), offers youth living with disabilities a means to learn the necessary skills for independent living in an inclusive environment that is supportive of their goals as they transition into adult life. While L.I.F.E. has always been an option for Holland Bloorview children and youth as they age out of our programming, coming together intentionally to "co-develop and co-lead Pop-Ups has enabled [MODC] to create double the impact for Holland Bloorview children and youth and for MODC" says Danielle Hepburn, Coordinator of Community Programs, MODC.

This partnership gives Holland Bloorview youth the opportunity to become aware of adult community program opportunities, such as the L.I.F.E. program. It also gives MODC the opportunity to increase outreach for their programs and engage more young people who can benefit.

Over time, as groups work together, new ideas can naturally emerge.

MODC and Holland Bloorview have had a long-standing partnership which has expanded and evolved to include Pop-Ups and other joint program delivery. Working together on the Pop-Ups inspired the idea of 'trial drop-ins' where younger age groups can try out the L.I.F.E. program and experience an adult community program firsthand before pediatric graduation. This kind of ongoing joint solution generating would not otherwise have happened without the Pop-Ups as the catalyst.

An increase in L.I.F.E. participant enrollment from the Pop-Ups has also, in part, enabled MODC to begin piloting an evening program of L.I.F.E. in 2023 to accommodate participants who are still in school. Overall, this partnership has been a mutually-beneficial experience for both organizations.

Example 4: Personalized Transitions Plan



Background

Resources and tools are widely available to support transition to adult life for young people with disabilities. However, youth and families have shared with us that the available tools are often too onerous, loaded with medical jargon, and not able to meet their individual and unique needs. A reimagining of a self-directed, practical, and user-friendly tool was needed.

Tenets in action:

- Human-centered design
- Collaboration:
 - Working with partners
- Working with children, youth, and families
- Solution-focused approach

Opportunity

The digital <u>Personalized Transitions Plan</u> (PTP) was developed to facilitate personalized and context-driven transitions for children and youth 14 years and older and their families. It is intended for longer-term use, starting when children and youth are still in pediatric services as teens and to be carried with them as they move towards the many transitions of adult life. The PTP can be used with youth and their families regardless of their plan to leave or remain at home as they transition to adult life.



The PTP was developed using a <u>human-centered design</u> approach (see <u>Appendix B</u>) and built upon <u>evidence-based</u> knowledge, current practice tools, and lived experience. Many groups collaborated to build the PTP, including: Holland Bloorview Transitions Strategy Team, <u>Family Advisory Committee</u>, families, youth, <u>community partners</u>, and other Holland Bloorview staff. It is designed to change the way that transitions have been approached by starting with the child/youth's context, best hopes, and preferred future vision using a <u>solution-focused approach</u> (see <u>Appendix A</u>).

About the Personalized Transitions Plan

The PTP is a self-directed, self-paced tool for children, youth, and families that can be completed individually or collaboratively with service providers. It aims to meet their needs as they move into adult health, social, educational, or other systems. It can be used as a conversation-starter to support planning for a meaningful adult life.

The PTP is integrated with Holland Bloorview Transitions <u>Pop-Ups</u> (i.e., Transitions Pop-Up: Create your own PTP), where children, youth, and families begin using the PTP and learn tips, resources, and next steps to support their transition goals. They can also receive coaching and one-on-one support from staff, parents, and caregivers with lived experience of transition, and students from the <u>OnTrack Transition SLE</u>.



Personalized Transitions Plan: Six key sections

The PTP includes six sections. Children, youth, and families select whichever section(s) are relevant to their current situation and can concentrate on different sections as their needs evolve. This contributes to the personalization of the PTP while also attempting to reduce feelings of overwhelm when using the tool. The six sections include:

ACCESSIBILITY SETTINGS (SECTION 1)

Tools and settings of the document that can be personalized to the child/youth's needs and preferences.

ABOUT ME (SECTION 2)

A profile of the child/youth's values, strengths, and supports that will be used to drive their future vision.

MY FUTURE VISION (SECTION 3)

Exploration of the child/youth's vision for life in young adulthood and beyond.

WISDOM FROM OTHERS (SECTION 4)

Advice and support from youth and families who have experienced the transition to adult life.

TRANSITIONS TOOLBOX (SECTION 5)

Tools and resources on a variety of relevant topics (e.g., social relationships, legal considerations, home and living space, personal care supports).

MY ACTION PLAN (SECTION 6)

A tool to organize, prioritize, and keep track of personalized goals.

The PTP includes:

- Prompts for time-sensitive activities (e.g., government funding applications).
- Links to existing transition resources and services.
- A combination of short- and long-term goal setting and action plans.
- Links to other existing plans in a young person's life (e.g., school transition plan from individualized education plan [IEPs]) with suggestions of how to integrate the actions of both.

Service providers may also wish to consider how the PTP can be integrated with discipline/sector specific tools (i.e., from Developmental Services Ontario, other employment agencies, or medical transfer tools) to maximize personalizing the tool.





Impact

The PTP was piloted in a Transitions Pop-Up with children, youth, families and staff from Holland Bloorview and March of Dimes Canada. Feedback from attendees (six parents/caregivers, two youth, and five staff) indicated that the process of engaging with the PTP brought up a mix of emotions for participants.

On one hand, participants expressed feeling anxiety, sadness, fear, and frustration about the volume and unknown nature of transition-related tasks and needs. On the other hand, some participants felt relieved, hopeful, and appreciative of the PTP in helping them stay organized and on track with their transition to adult life.

Participants also reported that the PTP helped them identify their needs and directed them to useful resources (e.g., links to external websites). After engaging with the PTP, participants shared concrete next steps for their transition journeys, including contacting adult agencies to learn more about new programs and reading specific tips sheets from the "Transitions Toolbox" section.

The PTP equips service providers to approach the topic of transition to adult life with children, youth, and families in a way that is supportive and child/youthcentered, recognizes individual and diverse needs, and is productive towards creating a plan for the transition. It supports children, youth, and families to participate in dedicated conversations about the transition to adult life during which they feel heard and valued so that they can determine tangible next steps to take towards their preferred vision for their adult life.

Other transition planning tools



A variety of planning tools are available from different sectors (i.e., education, employment, social services). Here are two pediatric tools developed within the Ontario healthcare context:

- SickKids: MyHealth 3 Sentence Summary
- CanChild: MyTransition App

For a broader range of planning tools developed in Canada, see the McMaster Health Forum rapid review:

• Identifying features of approaches to supporting transitions from child to adult care for young people with special healthcare needs (Voorheis et al., 2020) https://canchild.ca/system/tenon/assets/ attachments/000/003/208/original/supporting-transitions-rapid-synthesis.







Kyle Daly, a Master of social work student with the University of Toronto, is involved with the OnTrack Transition SLE and Transition Pop-Ups as part of his Year 2 fieldwork placement at Holland Bloorview. In this role, he works with the Transitions Strategy Team and students from other clinical disciplines to create and facilitate a variety of Pop-Ups.

In an inital Pop-Up, children, youth, and families are briefly introduced to the PTP and receive a copy of the resource. In a separate PTP-specific Pop-Up, attendees learn more about the tool, how to use it, and have dedicated one-on-one time with Pop-Up staff and/or trained healthcare students like Kyle to work on it. Using a solution-focused approach (see Appendix A), Kyle supports attendees to fill out the part of the PTP that is most relevant to their current transition needs.

Kyle says that "...some families know exactly what they want support with, like applying for ODSP [funding]. Some families have no idea, then it's my job to go through the PTP with them, validate that it can be an overwhelming process, and emphasize that they might not know everything that they need to know right now, everyone needs different things at different times. The PTP is very child/youth- and family-centered (...) it's their tool to use in a way that works best for them."

As a service provider-in-training, Kyle has learned a few things about using the PTP:

- It is a useful tool for service providers to build rapport with children, youth, and families.
- It can be overwhelming for children, youth, and families due to the volume of information. However, children, youth, and families have said that they value having all of the information in one place for if/when they need it in the future. This way the PTP becomes a one-stop resource.
- It is a great tool to focus service provider visits. The PTP is well-organized, and given that appointments are often time-limited, it can be useful to focus child/youth and family needs related to one aspect of the PTP (e.g., mental health supports).

Kyle emphasizes that it has been valuable to pair the PTP with a Pop-Up session and that the short presentation and extended one-on-one time with a staff member really cements children, youth, and families' understanding of how they can make the PTP work for them. Additionally, it pairs well with the other Pop-Up topics, which are aligned with different sections of the PTP, reinforcing that this tool can be used in different ways, as child, youth, and family transition needs evolve overtime.

As a student, Kyle has been grateful for the leadership opportunities offered to him by the interdisciplinary OnTrack Transition SLE and co-facilitating the PTP Pop-Ups.

He further shares that "working with students from other disciplines, and seeing how they view their work with children and youth has only improved my work!"



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In closing

To respond to the need for innovative transition solutions, we partnered with service providers, organizations, and system leaders, family and youth partners, and researchers, to re-evaluate how transitions are experienced, facilitated, and made meaningful.

Our approach was underscored by four key tenets: the use of Frameworks, a Solution-focused approach, Human-centered design, and Collaboration. These tenets represent our foundational approach to understanding gaps, needs, and opportunities before tailoring the creation of holistic transition solutions.

The objectives of this guide were to:

- Identify supporting evidence, some transition best practices, and impactful frameworks to guide practice.
- Discuss the role of a solution-focused approach to generate practical solutions for real-world issues.
- Describe the critical role that human-centered design can play as a transformative approach.
- Identify the necessity of collaboration with children, youth, families, services providers, organizations, and system partners.
- Provide tools and resources to support using the approaches outlined.

In this guide we have:

- Shared some of the evidence-based, evidence-informed, and practice-based ways in which we have actioned our tenets
- Explained how the tenets contributed to creating transition solutions and their impacts on children, youth, and families' experiences.
- Provided a variety of resources, mini-examples, and tips to use in ways that work for you.

We know that shifting the transition experience for children and their families from within our complicated health, community, education, and social contexts can seem like an enormous task. We hope this guide provided practical support that can help you with this important undertaking.

If you are wondering where to start, ask yourself: What is one conversation you can have today to influence the transition solutions of tomorrow?

You never know where a conversation can take you!



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Guide development process

Evidence to Care removes barriers to evidence use in practice.

As a team of knowledge translation experts, Evidence to Care (EtC) embodies "working better together" by partnering with clinicians, hospital staff, families, researchers, and community partners to close the "know-do" gap in the adoption of research evidence into practice. EtC brings their creativity, learning lens, and critical thinking to generate engaging and useful knowledge products for providers, children, youth, and families at Holland Bloorview and beyond.

As adept process experts, we:

- Draw on facilitation and design skills.
- Embody a solution-focused approach.
- Apply knowledge translation, implementation, and dissemination best practices.

EtC partnered with the Transitions Strategy Team to develop this guide using the principles of co-design: building trust, finding voice, sharing perspectives, and creating a common vision for change (Moll et al., 2022). As with many complex projects with team members from varying disciplines, navigating ambiguity and non-linearity was a key role that EtC held.

Over the course of this work, EtC worked with the Transitions Strategy Team to:

- Gather and synthesize information about their practice.
- Transform team thoughts into a succinct and engaging narrative.
- Verify, refine, and iterate guide prototypes.
- Integrate a high volume of feedback from internal and external reviewers.
- Manage expectations about the scope of this work.

To learn more about our approach to developing this guide, check out our accompanying resource on our Knowledge Translation Products website.





Guide contributors

This practical guide was jointly produced by service providers in the Transitions Strategy Team and knowledge translation experts in the Evidence to Care Team at Holland Bloorview Kids Rehabilitation Hospital.

The Transitions Strategy Team is a group of healthcare professionals, family and youth partners, clinical leaders, and researchers, who worked together over five years to explore, implement, evaluate, and share practices, knowledge, and resources related to transitions for youth and families living with disability. Team members worked with clinical teams, children, youth, families, and system partners to achieve the clinical, educational, research, organization, and system-change goals described throughout this guide.

Evidence to Care is an award-winning, specialized team that practices high caliber knowledge translation. Through collaborative efforts and application of knowledge translation science, Evidence to Care strives to make research evidence and expert knowledge accessible by promoting evidence-informed care in the field of childhood disability.

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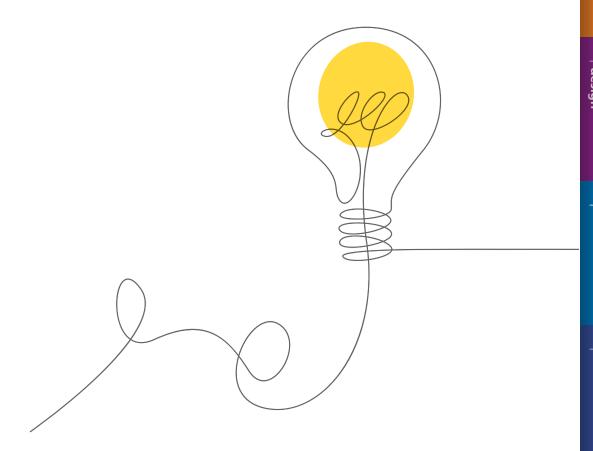
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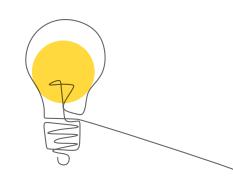
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Conflict of interest declaration

Guide contributors have no conflict of interest to declare.

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Holland Bloorview

Holland Bloorview Kids Rehabilitation Hospital is Canada's largest children's rehabilitation hospital dedicated to improving the lives of children with disability. As a hospital fully affiliated with the University of Toronto, we are home to the Bloorview Research Institute and the Teaching and Learning Institute, allowing us to conduct transformational research and train the next generation of experts in childhood disability.

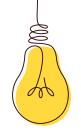
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Appendix A: Solution-focused approach support materials

Tools to support using solution-focused communication

Here are some generative tools you can start to use right away to support the integration of a solution-focused approach in your work. The content in this section was created using both existing literature and first-hand experiences of humanistic healthcare experts implementing a solution-focused approach.

Tool	What is it?
Question types	The questions we pose are our tools to support others to work towards their own solutions. We employ different types of questions at different points in conversations to support movement towards their decision.
Keywords	We know certain key words and phrases have a positive strategic influence on the conversation and the child/youth's functioning. We use these within each question type.
Prioritizing constraints: 'One foot in acknowledgment and one foot in possibility'	In many situations, there will be constraints around what we can and cannot change. Prioritizing these constraints is a tool that supports us to recognize, that despite constraints, possibility for growth also exists. It can be especially useful for children and youth with disabilities. As an example, transitions can be seen as a constraint: they will happen whether children, youth, and families want them to or not. This tool can be used to support them to navigate their transition options in a way that recognizes their inherent strengths and resources.

Note. Adapted from Cook (2022), King et al. (2019), King et al. (2022), and Seko et al. (2021).



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Question Types

In a solution-focused approach, we use different types of questions to elicit, amplify, and reinforce strengths and resources that children, youth, families, and our colleagues already possess. It helps to know how each type of question is helpful to you in your conversations. We have also listed what you want to be listening for as a child, youth, family, or colleague respond to your question. Some example phrases are listed in the subsequent table.

Question type	How is this type of question helpful?
Opening	At the beginning of an appointment or interaction, using specific rapport building and goal setting questions can help you to discover what the child, youth, family or colleague wants out of the conversation. Responses will help you gather details about their wants and needs.
Relationship	Relationship questions can help someone to consider the situation from an 'other' perspective. This can support someone to identify solutions that they otherwise could not understand because they are immersed in the problem. The 'other' perspective is ideally someone that the child, youth, family or colleague trusts and who may be an important relationship to them.
Scaling	Scaling questions can be used to set goals, assess where the person is now and readiness to change, monitor progress, identify strengths and resources, and explore potential next steps.
Coping	Coping questions are helpful in elucidating strategies they have used to date to address their problem. They also function as a way to give direct and indirect compliments. Direct compliments are a brief, positive verbal description of what you admire about the person. Indirect compliments imply something positive from a third-party or objective perspective. Both forms of compliments amplify someone's awareness of their strengths, resources, and ideas.
Outcome	Outcome questions are about a preferred future in which the problem is less prominent. This can encourage the person to think about a broader range of possibilities to address the problem in the present.
Exception	No problem is a problem 100% of the time at 100% intensity. Exception questions look to uncover what the person was doing previously or differently when the problem was less intense (even just a little bit) and what or who supported the occurrence of the exception.



Question Types (Continued)

Asking different questions: What am I listening for?

- What do they want?
- What is important to this person?
- What are they already doing?
- What is working?
- What will be different for them (the child/youth, family, or colleague) once they achieve what they are hoping to achieve?
- Goals related to: being, doing, belonging, becoming
- Realistic goals or changing goals
- Strengths, resources, or supports
- Very important relationships (can be a person, pet, or even stuffed animal)
- Readiness, understanding, or commitment

Note. Adapted from Cook (2019b).



Holland Bloorview solution-focused publications

Here are some articles that discuss the use of a solution-focused approach:



- Journal Article: The funnel of optimal functioning: A model of coach education (Cook, 2022)
- Journal Article: Perceived impacts of solution-focused coaching training for pediatric rehabilitation practitioners: A qualitative evaluation (Seko et al., 2021)
- Journal Article: Integrating lived experience into clinical practice: A case study of young peer providers in pediatric rehabilitation (Seko et al., 2022)



Question Types: Examples for children, youth, families, and colleagues

Here are some example phrases you can use with children, youth, families, and colleagues. You can modify them to meet the situation and your needs.

Question type	Children, youth, and family examples	Colleague examples
Opening	 When thinking about future life in young adulthood and beyond, my/our best hopes are How will you know that the (program, appointment) has been helpful for you? What do you want instead (of the problem)? 	 What are our hopes/needs for this service, program, intervention, resource, process, or tool? How will we know that it has been successful? What are the child's/youth's/ family's best hopes for their transition goal (i.e., life after high school, work, living independently)?
Relationship	When X happens, who will notice?Who will support you?I wonder how (identified close person) would have described that situation?	 What will we notice as this child or youth moves towards their goal? What are the other services involved in the child or youth's context that might notice or contribute to their care/goal?
Scaling	 On a scale of 10-1, where: 10 = my future vision is in place, and 1 = the opposite Where are you today? What makes it that number today? When you are able to move 1 number higher on the scale, what will be different? 	 Where is the child/youth right now with their goal? What would one small step be, in the next (reasonable time period), that the child, youth, or family has identified that we can support?
Coping	What did you do?How did you manage to do that?	 When we encountered this (change/choice/situation) in the past, how did we manage to support the child/youth and family? How did we manage to support each other?



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Question Types: Examples for children, youth, families, and colleagues (Continued)

Question type

Children, youth, and family examples

Colleague examples

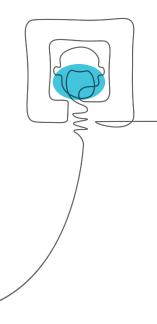
Outcome

- What might be different for you at a future date when the problem is less or resolved?
- What have you learned as a result?
- When we have met our goal, what will be different in our team? In the organization? In the system? How will we notice?

Exception

- Was there a time in the past where you experienced this issue? What did you do?
- What was helpful for you along the way? What else...?
- What is different for you as a result of this? What else...?
- When you have come to a choice point or faced policy/ system-related challenges in the past, what helped you move forward, even a little bit?

Note. Adapted from Cook (2019b), and A. Townley, L. Bowman, E. Cook, personal communication, (February 13, 2023).





Keywords

Keywords are used in conjunction with our question types. Although you can use any keyword with any question type, here are some examples where they fit well.

	What we use	Keyword rationale	What it replaces
General questions	Curious	Adopting a stance of curiosity helps the service provider to ask better questions. It invites collaboration, infers humility, and allows us to lead from behind.	A directive approach.
Opening questions	Helpful	Asking the child, youth, family or colleague "what might be helpful" or "useful" for them in the moment engages collaborative goal-setting, agency, and autonomy.	The service provider's expertise as the only source of expertise.
	Instead	What does the child, youth, family or colleague want instead of the problem they currently experience?	Problem-focused questioning.
Relationship questions	Notice	We can ask the child, youth, family or colleague what they (or someone else) "will notice when X (the person, or the problem) are even just a little better". Noticing is another executive functioning skill that encourages the child, youth, family or colleague to focus on what they want instead of the problem.	It is not replacing anything; it is a generative question that elicits strengths and resources.
Scaling questions	Might	Might is a way of softening or padding our questions. For example: "What might be your next step, despite your current challenges?"	It replaces: should, can, is. It gives permission to consider goals that seem too big or overwhelming without committing to a solution.
	Even just a little	Similar to "might", this phrase reminds the child, youth, family and the service provider that small differences can be good enough.	The inclination to focus on goals that are too big or overwhelming.



Keywords (Continued)

	What we use	Keyword rationale	What it replaces
Coping/exception questions	Despite (possibilities within constraints)	Prioritizing constraints encourages the child, youth, family, or colleague to have "one foot in acknowledgement and one foot in possibility." For example, "Despite all the challenges your family is currently facing, how have you managed to hold it together?"	Problem-focused questioning.
	Manage	Manage is also a positive assumption and infers that the child, youth, family or colleague has the ability or they are already managing to do things they may not even be aware of. It implies action and ownership of the ways that they are already making a difference that they may not appreciate.	Manage is also generative.
Outcome questions	Difference	Asking a child, youth, family, or colleague about the difference a choice, goal, or action will make for them highlights their values and engages critical thinking, agency, autonomy, and enduring personal resources.	Without asking about the difference, we may learn of the child, youth, family or colleagues' goals, hopes, or what their next steps might be – however we don't know what value that holds for them.
	When	"When" is a word that implies a positive assumption. For example: "in a few weeks, when you are better able to manage the workload"	It replaces the word "if" and implies our confidence that they will move towards their goal.

Note. Adapted from E. Cook, personal communication (August 22, 2022).





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Reframing common transition situations: What's possible within your constraints?

Often, transition situations happen regardless of choice, preferences, and/or desire for change. As a service provider using a solution-focused approach, you can support families by "holding one foot in acknowledgement of the challenges that transitions can pose", while also "holding one foot in the possibilities for the future" (E. Cook, personal communication, August 22, 2022).

Conversation starters can support reframing challenging situations, encouraging children, youth, and families to identify their hopes for an ideal situation. They also help to acknowledge potential "deal-breakers" given that many situations will not be their ideal, and how to take steps towards making these transitions a little bit better. Note that the questions are very similar regardless of the transition situation and can be used with children, youth, families, and colleagues. Here are some common transition situations and conversations that service providers have with children, youth, and families:

Common transition situations

- Changing service providers
- Long term goal planning
- Stepped goals (to get to long term goals)
- Starting a new school
- Finding housing support
- Transition of financial support
- Accessing attendant services
- Next steps after finishing school
- New life skills
- Change in social groups
- Families preparing for future legal and caregiving needs

How can I encourage reframing of a situation?

- What do you need from [situation]?
- In one to two years, what do you see your preferred [situation] being?
- What can we do now to get you one step closer to your preferred future?
- In your ideal future, when [situation] is working, what does that look like? What difference does it make for you? Who will notice?
- What parts of [situation] in the past have you found to be the most important?
- Given that [situation] is occurring, and with that comes [constraints], what might be one thing that we can do, to get you one step closer to your goal?
- What is the first small step we can take, in the next [realistic time period], to help you get there?
- What resources do you already have in place or are connected to that are working well?
- How might you find out what is available for you?
- Who in your support network might be able to contribute?

Note. Adapted from C. DuPré, personal communication (December 12, 2022).



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Using strategies to bring conversations back to the relevant topic

Here are some examples of strategies and phrases you can use when a webinar, session, or conversation has moved away from the topic at hand. You can modify them to meet the situation and your needs.

Strategies: What you are doing?

Create rapport and set goals:

Begin with good rapportbuilding and good goal-setting for the session.

Initiate frequent check-ins:

When the participants know the goal of the session, frequent check-ins can bring the conversation back to the topic.

Identify possibilities within constraints:

Use constraints, like session time and topic, to reorient the discussion.

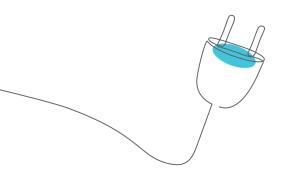
Use compliments and re-framing:

Allow participants to identify how they can bring the conversation back to the topic by reframing the situation using compliments.

How is this useful and/or what can you say to use these strategies?

- Without either of these the service provider has no direction.
- The service provider needs to know what the participants want and how they know the session will be useful to them (see <u>Opening Questions</u>).
- "I'm curious, are we on-track?"
- "Are we working toward what we agreed would be helpful or useful to you?"
- "Given that our time is limited, I'm wondering whether we can come back to this at another time?"
- "Given that we want to focus on [topic/goal], would it be more helpful for us to revisit this conversation a little later when we have more time?"
- "Wow, we are learning so much about everyone's strengths and resources, despite veering off course a little. What have we learned that might contribute to our topic in ways that are useful?"
- "This is a great conversation. I'm wondering how this might inform what our goals for this session are?"

Note. Adapted from E. Cook, personal communication (February 13, 2023).







Here are some things to think about as you plan for the human-centered design process. Also shared is some information on the stages of human-centered design and ideas for how you can enact these stages. The content in this section was created using both existing literature and first-hand experiences of the Transitions Strategy Team in implementing a human-centered design process (Bene & McNeilly, 2020; IDEO, 2023; Sandholdt et al., 2020).

Planning for human-centered design: Things to think about*



Project oversight and leadership

- Having designated leadership (e.g., core individual, team) helps to keep the work moving towards the shared goal.
- Leadership will oversee how and when sessions are held, identify groups for contribution, and guide the evolving prototypes within context.



Leveraging facilitation skills

- Skilled facilitation keeps the process on track so that session outputs are achieved.
- Thoughtful facilitation can foster a creative space, keep focus on empathy, and redirect individuals to focus on what is working and what might be different.
- When thinking about facilitation, ask yourself:
 - How comfortable am I with facilitation? Do I need training or support to help facilitate?
 - Should I look for experts in facilitation? Who in my organization could take on this role?
 - If I want children, youth, and families to authentically contribute, how can I/the facilitator work with a child/youth and/or family to design, plan, and facilitate a session?



Planning with purpose

- Each human-centered design stage occurs through a planned session.
- Planning activities to be completed in each stage and session keeps everyone focused and working towards the same output. This keeps the project moving towards the ultimate goal.



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Fostering creativity

- Creative strategies can help build trust through shared power while seeking solutions.
- Use a variety of strategies (e.g., ice breakers, music, props) to help shift stakeholder mindsets.
- Providing an open and creative space allows individuals to take a new perspective towards solutions.



Consolidating information

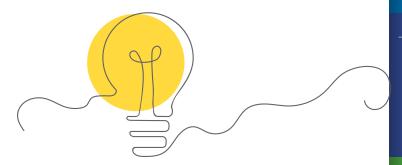
• Between each stage and each session, review and consolidate the information and ideas. This will help to refine the vision presented in the next stage, and keep the work moving forward.



Capturing multi-stakeholder voices

- Including perspectives from groups representing different stages of transition, roles, and/or organizations promotes greater diversity and problem-solving throughout each stage.
- Including perspectives from groups that may have barriers to engagement in collaborative activities, for example due to resources, time, accessibility needs, and/or language, encourages the development of equitable solutions.
- Consider how groups that do not normally work together might collaborate and discuss solutions from their different perspectives to gain new insights.
- Be aware of how each group can best contribute their perspective and be intentional in providing opportunities to share (e.g., how people are grouped in tables or virtual breakout rooms).

*Note. Adapted from Bene & McNeilly (2020), IDEO (2023), and Sandholdt et al. (2020).







Human-centered design in action*

Stage 1: Empathize (learn about the audience)

- Empathizing allows you to focus on:
 - Understanding current perspectives, practices, and realities for stakeholders (current state).
 - Understanding where stakeholders would like to be or how they would like to feel (desired future state) when things change (e.g., programming, support, funding, context).
 - Discussing challenges and how people feel about them and sharing what they would like to be different. Ideas of how things might change can help you understand the desired future state.

Empathizing in action

- Reviewing the literature helps to:
 - Understand how different individuals (more broadly) experience transition solutions beyond your organization's walls.
 - Provide examples of the solutions that have been tried, what the outcomes have been, and how well they have been received and aligned with stakeholder needs.
- Having conversations makes connections with stakeholders to understand their perspective on transitions. This can be done through:
 - Formal or informal interviews.
 - Journey mapping (a visual timeline of an individual's experience).
 - Bringing people together in the same room to brainstorm (ideation session).
 - Bringing the conversation and outputs back to desired feelings, states, and preferred futures for when the solution is available.





Stage 2: Define (sharpen key questions)

Defining the empathy-based goal and the parameters in which you must work (e.g., resources, frameworks) are important. An example of a transition-related goal might be: For children, youth, and families to feel supported and confident during the transition process.

Defining in action

- Creating a logic model provides structure as you consider your available strengths, realities, parameters, and where you hope to be at the end of this process.
- Establishing guiding principles shines attention on factors that can contribute to the collective goal, such as:
 - Frameworks you might be using in your practice.
 - Your organizational culture and principles.
 - How you carry out your role.

Setting parameters

Setting parameters is an important part of the define stage of human-centered design. Parameters contribute to clarifying and focusing the problem so that we might develop solutions that are actionable and context-relevant (Hasso Plattner Institute of Design at Stanford University, n.d.).

Here are some examples of parameters to consider:



Required resources

- Funding (e.g., build the solution).
- Collaborations with the community.
- Child/youth and family input.

Guiding approaches/philosophies

- Solution-focused approach
- Interagency collaboration
- · Child-, youth-, and family-centered philosophy

Constraints

- Budget time-frame (e.g., one month, two years)
- Availability of dedicated staff (e.g., two days/week)
- Unassigned space to conduct work





Stage 3: Ideate (brainstorm and create solutions)

- Brainstorm as a group to generate volume in your solutions: a large number of ideas, and ideas that are big! This involves:
 - Starting with "blue sky" thinking, where you think creatively without being constrained by resources (e.g., time, money, personnel) (McGuire Design, 2016).
 - Bringing ideas to life using strategies such as writing down what is needed or engaging people through creative approaches (e.g., art, acting).
 - Removing judgment (not labeling ideas as good or bad).





To stimulate "blue sky" thinking (McGuire Design, 2016), ask your stakeholders:

Suppose resources were unlimited, there were no constraints, and you had the ability to create a fabulous solution:

- What would that look like?
- How would that experience make you feel?



Ideating in action

- Hosting an innovation jam (a collaborative brainstorming activity) with small groups of individuals to:
 - Generate idealized solutions and consider how they might be later turned into prototypes and tested (e.g., through writing, models, or skits).
 - Present the idealized solutions, gain feedback from others on how they might be implemented, and iterate them into a new version of the idea.
- The idealized solutions generated will present the beginnings of tangible solutions to meet the needs of multiple groups. At this point, start to consider the practical constraints that are important and how they might be infused into the idealized solutions



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Stage 4: Prototype (build representations of more than one idea)

- Prototyping involves consolidating what was learned from creating the idealized solutions to form realistic prototypes that can work within the given constraints.
- Once a 'good enough' prototype has been created, take it to stakeholder groups and try it out. How this is accomplished will depend on the type of prototype that is generated. For example, if the solution is a program, you can do a mock run-through while others watch and collect real-time feedback. For solutions like tip sheets, you can lead a mock clinic or interaction with it and collect feedback on it.
- Using the feedback, revise, and iterate the prototype until it is ready to be formally tested in its intended setting.



What we mean by "good enough."

There is no perfect solution. Once a prototype is made that reasonably meets the needs stated in the previous stages (or provides a reasonable "solution"), it should be tried out with stakeholders. Now is the time to receive feedback and make sure the path you are on meets the needs of the various stakeholder groups (Sidebotham, 2017).

Prototyping in action

- Running a live-scale model offers real-time feedback by:
 - Demonstrating your solution (e.g., program) in front of an audience.
 - Inviting the audience to share feedback (e.g., audience members stop a live demonstration and share their feedback, or join the demonstration and describe what could be done differently).
- Scenario testing lets you take your solution and test it with different stakeholder groups. Have each group use or try the prototype and get feedback from the perspective they hold.
- Prototypes can be crafted written, acted out, sung, drawn, or in other creative formats that meet the needs of the situation and available resources.



Stage 5: Test (try out ideas and gain user feedback)

- After refining and iterating the prototypes with relevant stakeholder groups, test the solution in its intended setting (e.g., run the program a few times, share the resource in a beta version).
- Continue to invite feedback and evaluate the solution to determine if it meets the identified goal.

Testing in action

- Connecting with stakeholders helps to understand whether the solution helps them "feel" what they are intended to. Use different approaches to gather information (e.g., surveys, phone interviews, focus groups). Work to:
 - Identify what they found helpful and not helpful.
 - Determine what worked well and what did not work well.
 - Ask what can be done differently.
 - Then test, revise, and iterate.

Iterate: Keep shifting the solution to meet evolving needs

Remaining agile and assessing how the solution is meeting the needs of the different stakeholders is important. Contexts are always changing, and your solution may need to as well!



Continuing to understand stakeholder experiences and gathering feedback regularly can help you to review how the solution is working for them and iterate as needed. Make sure you have a plan to address the feedback you receive (Bene & McNeilly, 2020):

- Look at the stages of human-centered design and think about what elements of the process you followed that worked well and repeat them.
- Consider aspects of the solution that are still relevant and use these as your starting point. You might invite stakeholders to offer new ideas to add to/replace parts of the solution and try it out.



^{*}Note. Adapted from Bene & McNeilly (2020), IDEO (2023), and Sandholdt et al. (2020).

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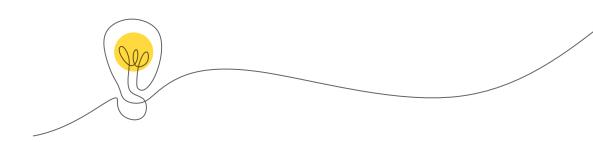
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