

The LIFEspan Transition Model: A Process Evaluation

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Table of Contents

Acknowledgments	3
Executive Summary.....	4
1.0 Introduction and Context.....	7
2.0 Evaluation Process.....	8
3.0 Critical Milestones.....	10
3.1 Pre-Development	10
3.2 Tipping Point	10
3.3 Development.....	11
3.4 Implementation	12
4.0 Enablers and Challenges.....	14
4.1 Enablers	14
4.2 Challenges.....	16
5.0 Replication and Expansion	21
5.1 Replication	21
5.2 Expansion of the Current LIFEs pan Model	25
6.0 Lessons Learned: Recommendations for Replication/Expansion of the LIFEs pan Model	28
7.0 Closing Comments	29
Appendices	30
Appendix 1: The LIFEs pan Transition Model	30
Appendix 2: Diagram of the Enablers and Challenges.....	32

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EXECUTIVE SUMMARY

The availability of and expertise to manage the ongoing healthcare needs of young adults with childhood onset disabilities is often limited and fragmented; in particular, the transition from pediatric to adult healthcare services can be challenging for youth and their families. The LIFEspan transition model (see Appendix 1), developed collaboratively by Toronto Rehab and Bloorview Kids Rehab, is dedicated to mitigating these challenges and facilitating continuity of care.

The LIFEspan transition model prepares youth and their families with the information and skills for active management of ongoing health needs. It also provides a coordinated transfer process into the adult healthcare sector through an outpatient specialized rehabilitation service. At this time, the model is focused on two populations: individuals with cerebral palsy (CP) and childhood onset acquired brain injury (ABIC).

The process evaluation of the LIFEspan transition model conducted by the GTA Rehab Network, sought to understand the development and implementation of the model in order to inform future replication and expansion opportunities. A longer term outcome evaluation, funded by the Ontario Neurotrauma Foundation (ONF), is also in progress (see Section 2.0).

Key findings and recommendations:

- Although the long term outcomes of the LIFEspan transition model have yet to be measured, overall it has met the goal originally set out within available funding.
- Critical milestones in the development and implementation of the LIFEspan transition model were identified:
 - Pre-development work, led by several ‘champions,’ laid the foundation for the development of the current model.
 - The ‘tipping point’ occurred when the CEOs of the two organizations put their support behind the model; as a result, the LIFEspan model became a strategic priority for both organizations.
 - Extensive research and consultation with both stakeholders and experts helped build an understanding of population-specific needs and further defined how the model could meet those needs.
 - A jointly appointed project coordinator and a funded demonstration project were critical in moving the model forward and ultimately supporting an application for funding.
 - Obtaining funding from the Toronto Central LHIN and hiring the LIFEspan team enabled the full implementation of the LIFEspan model in 2008. Since then, the LIFEspan model has met and surpassed nearly all of its previous goals related to the population served, patient satisfaction and patient volumes.
- Multiple enablers facilitated the development and implementation of the LIFEspan model including: trust and cooperation, leadership, goodness of fit and equity. Multiple challenges slowed down or changed the course of the model including: policies, procedures, personnel, physical resources, culture, practice and funding.
- Should the LIFEspan model be replicated, the principles of the model are readily transferable. These principles include the concept of ‘Growing Up Ready’ (i.e. early preparation for transitions, facilitating youth and families to take an active role in their own healthcare), an interprofessional approach to facilitating transitions, and linkage with adult services for a smoother transition between the pediatric and adult sectors, among others.

- A key pillar of the current LIFEspan transition model is the establishment of a partnership between a pediatric and an adult rehab organization. Replication of the current model in other areas of the province is possible so long as a comparable partnership among similar organizations can be established. Variations of the current program are possible and may include features such as enhanced community linkages, an adult provider 'home base' and a regional scope.
- Should the LIFEspan model be expanded to other populations, there is not much change required to the model itself; however, it is recommended that the funding, partnerships, staffing complement and expertise are also expanded relative to the expected increase in volume and complexity of the new populations. The current LIFEspan transition model and patient volumes support access for nearly all interested Bloorview patients with CP or ABIC; however, given limited resources, if LIFEspan were expanded, a review of triage/admission criteria is suggested to ensure that services are provided to those with the greatest needs for this transitional program.
- Populations which have been suggested by key informants for future expansion include: (1) spina bifida and neuromuscular disorders (plans already underway to expand to these populations); (2) CP and ABIC in the community; (3) pediatric arthritis and musculoskeletal populations; (4) pediatric transplant and cardiac populations; (5) pediatric oncology; (6) pediatric stroke; (7) respiratory (e.g. lung disease, cystic fibrosis); (8) complex medical (e.g. multiple diagnoses, long term health issues and mental health); and (9) new immigrants with childhood onset disease/disability who have never accessed pediatric services.
- Whether expanding or replicating the model, this process evaluation should be used to inform the development and implementation of future programs in order to preserve key enablers while managing potential challenges. Of note, some staff expressed feelings of conflict over not serving more than the CP/ABIC populations; given the likelihood of limited and/or incremental funding, it is recommended that an ethical framework for decision-making be referenced and communicated with staff.
- Process-related successes and challenges should also be considered in planning for future replication and/or expansion as well as to inform the current LIFEspan model.
 - Commitment from all stakeholders is essential; this includes commitment to adequate staffing, funding, space, etc. In particular, inclusion of the LIFEspan model as an organizational strategic priority has been identified as very important by key informants.
 - A jointly appointed coordinator can serve as a bridge between the two organizations and facilitate both the development of the model as well as the development of trust.
 - In order to benefit from the many advantages of a cross-appointed staffing model, find ways to mitigate the associated challenges, such as ensuring that communication, documentation, scheduling and other processes are streamlined for efficiency.
 - Develop tools to support mutual communication and understanding of how the collaboration will occur (e.g. through a memorandum of understanding). These tools will help build a sustainable foundation. However, leave room for flexibility as the collaboration evolves.
 - Equity in contribution, risk and decision-making at all levels is essential to building a true collaborative model. Invest in team building, and co-branding of the model.
 - In developing the program, look for corresponding programs between the adult and pediatric populations; by leveraging existing expertise and resources the early development can be enhanced.
 - Build in evaluation as much as possible. Setup clinical and organizational measurement tools.
 - Maximize use of available staff and ensure that roles are clearly defined. Consider use of alternate staffing such as family/youth facilitators to fill roles that do not require expert training.
 - Consider the extent to which existing internal services (e.g. AAC) may be able to support the model.

This process evaluation sought to better understand the development and implementation of the LIFEspan transition model as they relate to future replication and/or expansion. The model was found to have met its original goal although the long term outcomes (outside the scope of this evaluation) are still being studied. Critical milestones, enablers and challenges were identified (see Appendix 2) which will facilitate future development of similar transition models. The principles of the LIFEspan transition model as developed by Bloorview Kids Rehab and Toronto Rehab are readily transferable. Review of key considerations for replication and/or expansion as well as ‘lessons learned’ will help both current and future stakeholders in planning of youth to adult transition services.

1.0 INTRODUCTION AND CONTEXT

The GTA Rehab Network was funded by the Toronto Central LHIN in to conduct a process evaluation of the LIFEspan transition model and propose recommendations to integrate findings into expansion opportunities of the program.

The LIFEspan (*Living Independently and Fully Engaged*) transition model developed out of recognition of the need to better support young adults post discharge from pediatric healthcare services and entering into adult healthcare services. The availability of and expertise to manage the ongoing healthcare needs of young adults with childhood onset disabilities was identified by staff as limited and fragmented; in particular, the transition from pediatric to adult healthcare services are known to be challenging for youth and their families. The LIFEspan transition model was developed to mitigate these challenges and facilitate continuity of care through a unique collaborative model between two large rehabilitation centers: one adult provider, Toronto Rehab, and one pediatric provider, Bloorview Kids Rehab.

The model provides a two-year period of transition preparation for youth aged 16 to 18 and their families (see Appendix 1). During this time, youth and families are equipped with the information and skills to actively manage the youth's ongoing health needs and navigate the adult healthcare system. At the age of 18, LIFEspan offers a coordinated transfer process to either Toronto Rehab's outpatient specialized rehabilitation service for graduates of the LIFEspan program, or to other adult providers. LIFEspan services are provided by cross-appointed staff, who work at both Bloorview Kids Rehab and at Toronto Rehab. At this time, the model is focused on two populations: individuals with cerebral palsy (CP) and childhood onset acquired brain injury (ABIC).

The process evaluation of the LIFEspan transition model conducted by the GTA Rehab Network, sought to understand the development and implementation of the model in order to inform future replication and expansion opportunities. A longer term outcome evaluation, funded by the Ontario Neurotrauma Foundation (ONF), is also in progress (see Section 2.0).

Key Questions of this Process Evaluation:

1. What were the key milestones in the development and implementation of the LIFEspan program?
2. What were the enablers and challenges in its development and implementation?
3. What are the key learnings to be considered in the replication and expansion of the LIFEspan program?
4. What are the areas of expansion that may be considered in the future?

2.0 EVALUATION PROCESS

Evaluation Planning Process

Consultation with the LIFEsplan program for this process evaluation began in April 2009, when the Executive Director of the GTA Rehab Network met with the LIFEsplan steering committee. Following this, the GTA Rehab Network project team developed an evaluation plan in consultation with key members of the LIFEsplan project team (Joanne Maxwell, Joanne Zee and Helen Healy) and a representative of the research team involved in the ongoing ONF-funded study (Dr. Shauna Kingsnorth). Consultation with these key members facilitated an understanding of existing evaluations, created dialogue regarding LIFEsplan program evaluation needs, and confirmed the value of having a complementary process evaluation by the GTA Rehab Network.

Consultation to Leverage Existing Evaluations

During this process, the GTA Rehab Network reviewed the two main evaluations currently in progress to avoid duplication of work and to maximize value to future LIFEsplan program development.

Toronto Central LHIN indicators and internal scorecard: The LIFEsplan program collects and reviews data, such as patient demographics, number of patient visits, patient satisfactions scores, wait times and use of a self-sufficiency tool. This data is aggregated and submitted to the Toronto Central LHIN. Additional data points are also collected for an internal scorecard.

Ontario Neurotrauma Foundation (ONF) funded study: In 2009, the LIFEsplan program received funding from the ONF for a four-year prospective study, “A Longitudinal Evaluation of Transition Services” (LETS). This study will evaluate the processes and outcomes of the program:

1. *How the LIFEsplan model has been implemented under “real life circumstances” by describing the pediatric clinical interventions and processes of the two-year preparation period in detail (PROCESS EVALUATION); and*
2. *The impact of the LIFEsplan model on continuity of care, health, well-being, and social participation (OUTCOMES EVALUATION).*

While both the GTA Rehab Network and the ONF-funded evaluation focused on process evaluations, discussions with Dr. Shauna Kingsnorth identified that there were areas where the GTA Rehab Network could leverage the planned LETS study and provide added value to future planning of the LIFEsplan program.

- The LETS study aimed to evaluate whether clinical activities were delivered as planned (via chart audits). The GTA Rehab Network evaluation provided additional feedback on administrative and planning processes.
- The LETS study planned to interview key informants including frontline staff and project management team. The GTA Rehab Network complemented the ONF-funded evaluation by interviewing steering committee members from both the demonstration and the implementation phases.
- The LETS study focused solely on the implementation phase (Fall 2008-current), while the GTA Rehab Network evaluation encompassed the program development phase of the program (Demonstration Phase: Fall 2006-Summer 2008) in order to highlight milestones in the development process.

Collaboration

During the consultation process regarding the two different projects, an opportunity arose for collaboration between the GTA Rehab Network project team and the ONF research team, given the close parallels in the evaluations. The purpose of the collaboration was to generate a comprehensive picture of LIFEspan processes with regard to the development and implementation of this unique model, its challenges and successes in practice, and relevant issues for replication or expansion. This collaboration allowed for perspectives from all internal stakeholders to be captured. Once approval was obtained from both the Toronto Central LHIN and the Research Ethics Board of Bloorview Kids Rehab, the two projects were fully aligned for the collaboration.

Data Collection and Analysis

Both groups completed key informant interviews in Winter 2009. The GTA Rehab Network interviews focused on steering committee members while the LETS study interviews focused on frontline and management staff. Interviews were tape recorded and transcribed verbatim. Transcripts were anonymized; codes for identification of participants are stored in a locked drawer.

Because several participants had already been contacted as part of the independent studies prior to ethics amendment for a collaborative approach, all participants were re-contacted for permission to share anonymized transcripts with the rest of the team prior to the merging of data sets. Only the transcripts of those who provided consent were shared between the two teams.

- A total of eight steering committee members were contacted for participation in the interview; seven consented to take part. Of the seven steering committee members interviewed, six provided consent to share their anonymized transcripts.
- A total of ten frontline/management staff were contacted for participation in the interview; all consented to take part and all consented to share their anonymized transcripts with the GTA Rehab Network project team.

Joint analysis was completed in February 2010 to manually identify and code themes related to the development and implementation of the LIFEspan program, its replication, and its and expansion. A meeting with key stakeholders in March 2010 validated the key findings and themes and generated further discussion about how the LIFEspan program could be applied to other populations or settings.

3.0 CRITICAL MILESTONES

3.1 PRE-DEVELOPMENT

Pressure within the Pediatric Sector

Analysis of the transcripts identified that the development of the LIFEsan model evolved out of a need to bridge the gap between health care services for the pediatric and the adult populations. One participant described how this gap may have evolved:

...Our pediatric wait times [were] growing so, children...[were] having to wait for services because Bloorview was continuing to see adults and they were seeing you know people who were 30, 40, 50 years old with childhood acquired disability in a pediatric facility...so that was really a growing pressure

Seeking An Adult Receptor

This growing pressure in pediatric sector was impacted by the fact that there was never an “adult receptor” for the “graduating” pediatric patients, resulting in challenges accessing services in the adult sector. The LIFEsan program was described as one that had succeeded after previous attempts to engage various adult partners had not:

I've worked in the field of adolescent rehab...and have gone through many decades of attempting to reach out to adult partners, at every level from straight OT to OT to manager to manager, to director to director, we've tried a few bits and pieces along the way, seem to have some tentative agreements along the way, but nothing ever really worked. Some of them were in fact quite a fiasco, so I would have said that my focus as a clinician was always on the development of linkage with the adult system, and the history has been absolutely poor

Champions

Numerous participants in the interviews recognized the key role of champions in keeping the momentum going through the challenges of the pre-development time period of the LIFEsan program, as well as subsequently. Notably, the frontline staff were strong advocates for a transition program, with certain key team members consistently mentioned throughout the interviews.

3.2 TIPPING POINT

CEO Support / “Just do it”

The analysis of interview transcripts across the staffing groups related to the development of the program clearly pinpoints a common understanding that CEO support was a critical milestone in the development of the LIFEsan program:

The next important step which... was key for us...was a meeting held by, the CEO of Bloorview with the CEO of Toronto Rehab and at that meeting [a presentation was made] related to the issue. So when that was presented to the executive level of both organizations, the response was similar to the response that's always been there, which was, agreement in principle, yes it should happen, yes we all have the responsibility, but, but, but, and the buts were things like we don't have the proper clinics, we can't surgically implant baclofen pumps, we don't have the

right...people on staff, and there was a three quarter [of the] discussion on the barriers. And at the end of that discussion, the CEO of the adult facility turned around and he said, 'Just Do It.'

He said, we've listened, we've made our excuses, they'll always be there, 'Just Do It.' We agreed that both organizations had a small bit of pilot money, so let's just try it. And that was the tipping point if you want to use the classical analogy of the tipping point, that was the tipping point where it went from 40, 50 years of "We should" "We could" "We might" to "Let's Do It."

[CEO engagement]...kind of opened the door to them creating operating initiatives and indicators on the strategic plan that moved this forward. So that was probably critical in the early going.

Strategic Plan

CEO engagement was described as a critical milestone which put LIFEsplan on a list of priorities for both the pediatric and adult facilities. Becoming part of each organization's strategic plans was identified as an additional key factor in the development of the LIFEsplan model:

First one is...getting it on [the] organization's strategic documents. 'Cause if it's on there it has to be accountable...if I were working with another organization, I'd say, get it on the agenda as a strategic direction. Or a key goal for the organization, or on the report card or something, that gives it that level of exposure.

3.3 DEVELOPMENT

With CEO support and priority placed on the development of the LIFEsplan program, funds were allocated from both organizations to support a small a needs assessment, hiring of a project coordinator and the beginning of the pilot program, known as the "demonstration phase."

Needs Analysis and Stakeholder Engagement

The needs analysis was a critical step in forming an understanding of the key issues faced by graduating pediatric clients into the adult sector. While the needs assessment was completed in 2003, numerous discussions were held with potential clients and families as well as visits to current adult providers and similar types of programs already in existence in North America. All of these key steps built a foundation of best practice, active stakeholder engagement and a thorough understanding of potential medical and rehabilitative needs prior to selecting a population for focus and prior to developing a full model that could be operationalized.

...we realized that...some of the key issues were medical needs of the population, or sort of long term care as well as periodic bursts of therapies, spasticity, things like that... that was one of the key milestones.

...there were trips to visit other clinics...where there were "Lifespan" or transitional programs, some in the US, some elsewhere in Canada...we were looking for gold standards and then continued those connections ... to have that ongoing feedback about how were we doing...

...we did...speak to advisory committee council and family advisory council, and I think that was sort of important voices of families right from the start...we did engage quite a lot of people as we were developing it...a big part of what I did for the first year was go and talk to people. So talk to

community agencies that provided respite care, that provided attendant care, that provided health services, looked at these people as adults.

...we held a...meeting with some world experts on transition and...we had a consensus panel about what the model might be. So we developed the idea that you need to have cross-appointed staff and I think that was an important element of having some feedback from people from around the world...

Hiring a Project Coordinator

In May 2006, a project coordinator was hired jointly between Bloorview Kids Rehab and Toronto Rehab. The project coordinator oversaw the demonstration phase, led the preparation of the business case proposal for funding and was seen as 'the bridge' between the two organizations.

...when we went into the demonstration phase...the critical piece was having the jointly appointed coordinator that looked at the demonstration phase which was the 30 patients that we committed to see.

Demonstration Project

The actual demonstration project in and of itself was considered a key milestone where all previous efforts in building a collaborative model, determining best practices and identifying patient needs came together to be operationalized as an actual program. The demonstration project started in November 2006 with funds and staffing allocated from both organizations.

...the demonstration project was 'lets do this anyways... let's carve out a little bit of resources from neuro-rehab, let's have us run the program without the... funding from the LHIN and lets demonstrate that it's feasible to do this...we committed that we would...set aside some resources and that we would do 30 cases and we would just do that. And so that was a good start. And we had some therapists, some physios, speech, set aside...

We committed to seeing 30 patients, creating a model of service and you know looking at the outcomes for those 30 patients. And you know the outcomes were astounding, and that helped us with information that we then submitted a proposal, to the Toronto Central LHIN for... actual service.

3.4 IMPLEMENTATION

Funding Opportunity

A funding application was submitted to the Toronto Central LHIN in September 2007 for a phased approach to the LIFEsplan transition model, covering multiple populations, including cerebral palsy, acquired brain injury, spina bifida, muscular dystrophies and musculoskeletal disorders. In February 2008, funding approval was received, however only partially, and as a result, the LIFEsplan steering committee focused their initial efforts on the CP and ABIC populations.

Despite receiving less funds than originally proposed, obtaining funding was noted as a key milestone. Funding enabled full implementation of the program.

I think, having base funding, was absolutely critical, so that we could actually develop a program appropriately, and put the infrastructure in place to do the evaluation and the ongoing quality improvement.

I think the decision of the senior management that we were looking at a request for funding was another important milestone, and then it was not something that you could do with the existing staff or sort of the reallocation of existing operating funds...

Full Implementation

The full team was in place by fall 2008 and the full program as it is today has been running since then.

A full year with one team, that was our big celebration, like, the fact that we'd made it through a year with one team I think that's been important too.

Meeting the Intended Goals

The original goal of the LIFEsSpan transition model was to provide tools and education for the CP and ABIC populations at Bloorview Kids Rehab who were reaching the transition age and to facilitate the transition to and linkage with adult healthcare services. Although there was recognition that the long term linkage with coordinated adult services had not yet been evaluated, all key informants identified that the initial goal of the LIFEsSpan service had been met for the CP and ABIC populations.

Data collected by the LIFEsSpan program validates these experiences of the key informants and indicates that LIFEsSpan has met and surpassed many of its previous targets.

- An average of 63 clients with CP and 41 clients with ABIC turn 19 each year. 100% of these patients are offered the option to go through the LIFEsSpan program though not all accept; as a result, currently 55 to 60 new clients with CP/ABIC are referred for transition to adult services (up from 43 in the 2007/2008 fiscal year) and 54 to 64 new clients gain access to adult LIFEsSpan services (up from 32 in the 2007/2008 fiscal year).
- The number of visits has also increased since the beginning of the program. While in the 2007/2008 fiscal year, there were less than 500 visits to LIFEsSpan services, the model is now able to process 2000 to 2500 visits.
- 85% of patients in LIFEsSpan clinics are using the Growing Up Ready tool and patient satisfaction is high at 95%.

4.0 ENABLERS AND CHALLENGES

4.1 ENABLERS

Multiple enablers facilitated the development and implementation of the LIFEsSpan model including trust and cooperation, leadership, goodness of fit and equity (see Appendix 2 for diagram of contributing enablers and challenges).

Trust and Cooperation

A key enabler in the success of the development and implementation of the LIFEsSpan model was attributed to the building of trust and an atmosphere of cooperation among all staff. Some of the trust was built on the pre-existing person-to-person relationships; however, much of it came from a strategic collaboration among the leaders. The leaders upheld values of collaboration and partnership and presented a united front.

I've compared it a lot of time to a marriage because it is... a dating relationship, and sometimes I trust you, and sometimes I don't and ...there's one or two occasions where I know that somebody from a different level of management in one of the organizations came into our meetings and really very quickly he almost derailed things. Unwittingly... they came in with kind of the philosophy of well we're in charge here. And you had to, you had to slow them down and say, "Remember."

Even though philosophically and management wise,...process wise, policy wise, it might all look like this is plain sailing, but [building trust] really comes down to individuals. So I think that we worked very hard with that.

The opportunities for collaboration were appreciated by staff, particularly through shared learning opportunities and discussion.

It was always very collegial, and even when there were sort of discussions around who were we going to involve, it was always very professional, there was always consensus that everyone felt.

I think it's fun to have a partner over across to the adult site, and being able to kind of...put two heads together. And even though I am alone on the team because there is only one of each discipline, but to have a partner on the other side to say, "hey! How is it going?"

Leadership

Numerous leaders facilitated the development and implementation of the LIFEsSpan model. Long time champions of a transition model laid the foundation for the model's success. The CEOs of both organizations created the 'tipping point' (see "Critical Milestones") for the model by taking on the challenge of an underserved population.

The CEOs of both organizations embraced this, philosophically, moving forward, and that complemented, that already existing front-line relationship. So right the way across the spectrum of services, and programs you've got that connectivity.

The steering committee provided guidance for the broader direction of the program development and expert team members from both Bloorview and Toronto Rehab led education and collaborative opportunities. All stakeholders were willing to get involved; as one vice-president explained:

And the lesson learned for me was you know here I'm thinking, as a VP I shouldn't have to deal with that. Our manager should be dealing with that. In projects like this, you have to be willing to get your hands dirty to make things happen.

The leadership of Joanne Maxwell, Helen Healy and Joanne Zee, however, was critical in moving the model forward. The trio of leaders provided a balanced and united approach to collaboration and were noted to bring groups to consensus as a team in a seamless manner. In particular, the role of the project coordinator was highlighted numerous times as one of the critical enablers to the project because of the structure of her role.

Strategically we did hire someone that didn't belong to any one of the organizations and I think that actually helped build trust.

...She's a critical enabler of this project, it's a lesson learned...that in things like this ...having a champion and a glue that's bridging the gap, between the two places... is more important than any other steering committee, that you could create..

Goodness of Fit

There were numerous examples of how a 'goodness of fit' enabled the collaborative model to move forward between Toronto Rehab and Bloorview Kids Rehab. Not only were the two organizations close in proximity, but they shared very similar values and missions.

This isn't just about operations and making, making a program happen between two environments, this is philosophically this was the drive and desire and lay within the mission of both organizations. So I think strategically and operationally there was a fit from the partnership perspective and then that was um, that was lived out through the committees.

In addition, there was the additional advantage that one of the populations, ABI, was already a population that Toronto Rehab had expertise in, allowing leveraging of existing programs.

Equity

The concept of equity was common across many of the participant interviews. Equity was identified as an enabler with respect to contributions, development of the model, funding, and risk. Both organizations put in an equal amount of support toward the project through the CEO involvement, the presence of senior management from both organizations at steering committee meetings, through the sharing of staff and space, as well as sharing the risks of the demonstration project.

There was an equity in contribution, both personnel so in-kind, as well as committee membership, as well as co-funding, moving forward. So I think and the other element was the shared accountability.

Even at LIFEsan meetings, the location was rotated evenly between the two sites and the priority was placed on consensus, as one participant stated:

There was no there was no winner at the table, it was about building the best opportunity for the process moving forward.

Of note, in the implementation of the model, staff from both organizations worked together to build a new identity for the LIFEsan transition model in a 'co-branding' experience.

There was a, there was co-branding of this experience. It wasn't owned by Bloorview, it wasn't owned by Toronto Rehab, so there was a, a new image, new logo, new branding. So that you felt like you were part of something that very much was the integration of both of our environments, it wasn't going to be, "Oh I'm working on this for them, or they're working on this for me." It was very much, "ours."

4.2 CHALLENGES

For the purpose of the analysis, challenges were defined as those factors which slowed down or changed the course of the model. In the development and implementation of the LIFEsSpan transition model, several challenges were noted, including infrastructure, practice and funding.

Infrastructure

Policies and Procedures

Notable challenges were identified related to policies and procedures of the two organizations and how the two did not initially align. The logistics of a jointly funded model and a shared management model created the need for extensive communication between the human resources (including unions), finance, risk management, communications and other departments from each organization. Issues such as how to negotiate performance reviews, vacation time and even corporate training were mentioned. Strategies utilized to mitigate these challenges included extensive negotiation with senior management from both organizations and the development of a memorandum of understanding to outline the agreements made.

Now that sounds simple, you're hiring somebody for two organizations, come on, this is their job. That was incredibly difficult, because one...facility is unionized and one isn't, so you even got into things about posting. How can you post, who does it have to go through, who does it have to go by um. How are we going to disperse...remuneration.

...those sorts of management issues that are silly and picky.. but as I said, project development is easy if you're doing it in an office, and you're not talking to anyone. Very easy... But if you're actually, working it out, then you forget that you need HR, you need public relations, you need, if you're putting out press statement, to have our public relations agree with their public relations...sometimes you honestly felt like you were in a dating service...putting these people together and saying,... "You can't do it exactly the way you'd always do it, because they have a different way." So it was that sort of nitty gritty small things, but they made a huge difference. And setting up that trust took about a year.

Personnel

Another challenge was in defining, recruiting and managing personnel. For example, even when the logistics of a jointly appointed staff model had been determined, the recruitment of staff, particularly of a nurse practitioner, posed another challenge to the LIFEsSpan program.

It's very hard to find a nurse practitioner we...wanted the linkage to be the nurse practitioner...so it's only being really since August of last year, 2008 I guess, when we sort of had the whole team and it's just now that we've worked out all the details around moving people.

I didn't realize we'd have such difficulty recruiting. And how long it takes to recruit.

In addition, while the cross-appointment model was highlighted as a strength of the LIFEspan model, it also brought its own challenges. The fact that a cross-appointed staff physically worked at both organizations on alternate days brought about difficulties in managing schedules, communication and even team building.

I think there is a disconnect, like an emotional disconnect between the team members because we don't know each other very well. And when you think about it, we have one day a week when we do clinic together, and all the other days we are running around doing our separate things. So it's hard.

At times it was noted that understanding of each other's roles could be challenging at times and that better role definition could maximize use of available personnel and time to best serve the patients.

How do we maximize the time that we are spending with the client and get rid of some of the territory issues that come along. So it's really more where the challenge is, broadening our think to a transdisciplinary model.

I think it probably needs some hands-on work...to help us work on our team-work and understand each others' roles. And more work on understanding the differences between an interdisciplinary and multi-disciplinary team. Because I think that that sometimes can make a team not function well because there are no two people that are doing the same profession, but there is many people doing the same thing, which is trying to improve outcomes for clients.

The differences in management structure between the two organizations was noted as a challenge from a clinician's perspective as well as from a change management perspective. From a clinician perspective, working for multiple managers under a cross-appointment model required flexibility in approach.

...At [our organization], if you want to start up a new group, you...go up to your manager and say, "hey, I've got this idea," if [the] manager thinks it sounds good, you go with it, and you do it. And at [their organization], if you have an idea for a new group, you have to write a case...there is just a lot more process involved. So merging those two sort of philosophies...is very unique. And has its challenges at times.

From a change management perspective, it was noted that the pre-existing organizational structures may have slowed down some processes.

You don't necessarily get the budget and staff all neatly under one director, so often there's some realignment that has to happen...that again is something that can get you into trouble unless you recognize it.

Physical resources

Differences in physical resources to support the LIFEspan program were identified through key informant interviews, such as building accessibility, equipment and information management. While Bloorview had a relatively new and accessible building for example, the adult services at Toronto Rehab had some limitations in physical accessibility due to the age of the building, particularly a lack of accessible bathrooms.

... you want people to be able to access everything when they come...

Discrepancies were also noted in how readily available equipment could be obtained between the two organizations. It was noted that while these resources seemed to be easily acquired at Bloorview Kids Rehab, the same was not always true at Toronto Rehab, causing frustration for staff over the delays.

...Here we are trying to attempt to create something big, and the things that were bogging the teams down were the mundane things, oh, the equipment hasn't arrived, and the purchase requisition hasn't been processed and I would think at steering, you know what I don't want to hear any of this, because we are losing sight of the big thing that we are trying to create. So some of the organizational barriers on both sides were particularly on our side...they were more barriers and HR and support service...purchasing things...were headaches, like you wouldn't believe. But we got through them.

Finally, one of the biggest challenges in the day-to-day implementation of the model was in the difficulties aligning the information management tools of each organization. In particular, health records were a challenge due to privacy and logistic issues where staff were having to find alternatives to physically transporting a chart back and forth between sites. Because an electronic health records system was not available, alternative measures were used, however, the challenge was still marked as an important area for process improvement.

The [Bloorview and Toronto Rehab] systems just don't interdigitate very well.

...Sometimes the consent forms are completed here and no information gets transferred over the kids are coming over for their transition visits, and they have no background information on them. And then sometimes, some information gets sent but not everything that you would want to be sent...some of these are just those practicalities that...just, you know, get in the way.

Practice

Culture

While Bloorview Kids Rehab and Toronto Rehab were noted to share many similar characteristics and values, differences were reported in terms of culture, including culture of a pediatric as compared to an adult provider, typical length of relationships and the role of the family and the patient. The pediatric provider was perceived as typically having a primary focus on a family-centred approach, while the adult provider typically focuses on a client-centred approach. The pediatric provider was also noted to tend to have a longer relationship with their clients. On the whole, the challenge of cultural differences needed to be dealt with at both organizations.

The differences are the differences that occur between the pediatric and the adult services, where the pediatric services...often see the family first and the child second....we have seen the parents as the guardians and the advocates for so long...And we are working with the...transitions group to help... encourage the...young adult in the areas of self advocacy and communication. The adults' world expects the...young adult to be that independent advocator, often to the point that they will exclude the family from the appointment. Which puts the individual with developmental issues at a real disadvantage. So that has been a bit of a hurdle. I think we are far better with it now with the two facilities at problem solving around it and communicating it

Model

As a result of the cross-appointed staffing model, staff at both organizations faced difficulties ensuring that all essential information was readily available when needed, regardless of which site they were at; simple

daily tasks, such as scheduling, checking two emails and two voicemails were identified as areas where process improvements could be made to maximize clinician's time use.

I think the whole concept of working across sites puts a number of barriers in place, many of them practical. Simple things like accessing email, or not being able to send email from Bloorview site to Toronto Rehab site because of privacy issues, but they don't have one common email, so having to maintain two schedules, having to maintain two email accounts, having to check both places...That...probably adds a lot to the non-functional components of the job, which probably detracts from clients care.

Learning about the models of practice in use at each organization also created some challenges for staff to ensure that they utilized different models of practice. For example, while the pediatric service offered a more consultative role, the adult provider actually offered direct intervention; the cross-appointed staff would need to keep this in mind as they move from one site to another on any given day.

The two clinics, although they are called the same thing, offer very different model of service. So Bloorview's is a consultative model, where we're not doing any direct intervention, and TRI's is direct intervention. So for those people that are cross-appointed, remembering that they are in different spots, and have different roles and different ways of working with clients was challenging. Definitely.

Role division and definition was an added challenge, not just for LIFEspan staff working in a new team, but particularly for cross-appointed staff who were working in two different teams.

...When you bring in a new group of people together...Having a challenge with not a clear division of roles, is quite challenging....we could be in the first day interview with the client, we are...paired up but we don't know what each other is covering. So because of that overlap... families are...completely overwhelmed. They are there for three days, and they are being asked all the same questions over and over again, and each professional involved feels that it's important that they ask that question. So it's important that maybe we look at what the clients need

In addition to the cross-appointment model, LIFEspan was also based on a nurse practitioner (NP) model. While the NP model was preferred for LIFEspan, it also caused challenges in that it was very difficult to recruit a nurse practitioner, particularly one specialized in pediatrics. One participant even suggested that a rehab provider based model may be an alternative model for consideration given typical availability of NPs.

In hindsight...if we'd driven with extended scope rehab practitioners,...rehab players from my experience in the adult setting has a lower turnover, than the nursing players...I think that's a different way to look at it, you have to look at the people that you've got, and the passion that you've got and...who is the most likely to continue their commitment or to be able to be replaced. So, how many pediatric nurse practitioners have we got? Well...there was only one.

Finally, as Bloorview underwent a culture shift to encourage 'graduates' to utilize adult healthcare services, some confusion was created for their former clients who now had to distinguish between services which remained accessible to them as adults, and services which were not. Some services remained accessible due to funding regulations.

Another thing about the challenges of the model is the revolving-door thing....Bloorview offers services for dentistry, prosthetics, orthotics, and some of the programs in wellness and life-skills institute that also go up to the age of 25, family support service... so there is a bit of a confusion,

'cause...[the young adults] may be graduated but yet still come back for their dentist appointment here, and they want to know why...

Funding

Funding both slowed down and changed the course of the LIFEsSpan transition model. Participants described the ebbs and flows of the timelines surrounding the funding process as a challenge to sustaining team energy.

...You have periods of very fast driving because there's a deadline, a funding deadline and then...there was this kind of waiting time...I think that the energy and the continuity was probably a challenge at that point in time

...We had hoped to expand more quickly, into other client populations and again the expansion of funding slowed that down. So I think some of the initial excitement and energy may have washed out a little bit, because of those delays.

On the other hand while some funding processes slowed things down, at other times, the funding process required the team to work very quickly.

...We were notified of our funding in January, for January to March, so basically you know we need to have it up and running in a really, really short period of time, so I think that was a challenge.

Some staff recognized the pressures of needing to meet funding requirements, such as meeting target volumes, and found it challenging to work.

...Not that it's discussed all that often, but I think because we know that the numbers are continually being counted, and we are continually being asked for attendances...has created that sort of feeling of urgency that I need to keep my numbers up, which created I'd say a bit of competition about, you know we're trying to decide who we are going to go and see, and you know at times this has impacted on the effectiveness of the service.

Of note was that Augmentative and Alternative Communication (AAC) services were not a major component of the funding request with the assumption that internal resources would support this need; however, this was not the case. Funding needs for AAC services was noted as an area for future consideration.

We had just assumed our organizations will meet their needs. For example, AAC services for LIFEsSpan have turned out to be a real issue. The assumption that organizations will just make their own resources available without being compensated, has not turned out to be the case. I think on that one, we could have done things a little bit differently.

One of biggest challenges related to funding, however, was in trying to balance the expectations of all stakeholders while working within the available resources.

All of the other programs ...are saying, "Do more with less..." And we were saying, we wanted to do less with more... there was some tension... around that.

One of the challenges...was moderating blue sky hopes....both sides wanted everything perfect. And you can't achieve that. There has to be...give and the finding of a middle ground and sometimes that was difficult.

5.0 REPLICATION AND EXPANSION

5.1 REPLICATION

The Principles of the Model vs. the Supporting Factors

In considering replication of the LIFEsSpan transition model in other regions of the province, this report differentiates the model and its principles as compared to the replication of the current setup of the program structure. The *model* provides the underlying values, mission, beliefs and goals which guide program development (See Appendix A). The *supporting factors*, on the other hand, reflect the application of the model given the resources and stakeholders available; in this case, the model has been structured as a partnership between a pediatric and adult freestanding rehab hospital within a large city.

Replication of the LIFEsSpan Transition Model

Key informant interviews consistently highlighted that replication of the LIFEsSpan transition model is possible and that it would not require much change, regardless of geography, culture or population group/diagnosis, as long as the key enablers were in place (see “Enablers and Challenges”). This includes the ‘Growing Up Ready’ initiative (i.e. early preparation for transitions), facilitating youth and families to take an active role in their own healthcare, an interprofessional approach to facilitating transitions and the linkage with adult services for a smoother transition between the pediatric and adult sectors. The principles of the model were perceived to be ones with sufficient flexibility and universality to meet the transition needs of all pediatric clients who are approaching the transition age and requiring linkage with the adult health sector.

I've been a part of this team for a very long time...and worked with many different people. It's taught me that the model stays the same but the approaches change. And so being able to realize the end goal...no matter how it gets done, to realize that that is the important part, has been a change for me

While there are suggestions for change and improvement (see “Lessons Learned”), the model is recognized by almost all of the participants as being one that generally works as is and one that does not require modification. The key informants did, however, acknowledge that replication may or may not have the same supporting factors of the current LIFEsSpan transition model.

Replication of the Model with the Current Supporting Factors

Our model is based on partnership. If there is an adult partner that's willing to take on other groups then the model can work anywhere...I think that model can be done with anyone as long as there are two organizations that can be in partnership to provide[service to] the clients and be willing to take on the clients

The current LIFEsSpan model has been implemented based on the key supporting factor of an adult rehab facility and a pediatric adult facility willing to collaborate in order to deliver services within the transition model. Staff members are cross-appointed and physically work at both organizations. Replication of the current structure is possible in alternate regions, particularly if the key enablers are preserved. The value of the breadth and depth of expertise available within the LIFEsSpan team and the critical mass of clients needed to support a full LIFEsSpan team was emphasized by the stakeholders as a very important consideration. These are likely to be more readily available within larger regions.

...we developed a model we could then translate into other LHINs..the logical places that this can occur are those places with both children's centres and rehab centres. So, reality...is that there might only be six or seven centres in Ontario that could actually run a model like this...but you can't...run it everywhere.

There are clear advantages to the LIFEsSpan transition model being housed within two freestanding rehab organizations, such as ease of access to populations, expertise and infrastructure. Interviews and discussion with key stakeholders indicated that replication of the LIFEsSpan model may not necessarily need to be a collaboration between a pediatric and adult freestanding rehab facility, per se. Alternate structures may be considered (e.g., partnership with a family health team or community health centre) so long as the key enablers are in place.

Need for an Adult 'Home Base'

Participants highlighted the need for both community linkages and having an adult receptor as a 'home base' is important to supporting a successful model.

... I think that as we grow and evolve, really looking at our community partnerships, and dedicate time to develop those, that yes, the LIFEsSpan model will continue to work because we will be referring clients out and have us only as a home-base.

In particular, having an adult receptor was identified as key in ensuring the availability of an interprofessional team with sufficient expertise and resources to meet the ongoing complex needs of the adult population. As one participant described, *"It is not the hospital that is critical but the team in the clinic."*

In particular, as children with disabilities age, there will be increased demand to evaluate their long term needs within the adult sector. The role of an adult provider was described as a hub where patients could come in with issues and get referred out to community providers as needed, with ongoing dialogue between the community and the adult provider.

I think long-long-long-term goal is then setting up the capacity in the communities. And then kind of extending that out, you know you can follow that individual and we're here for all the questions that you're not going to be necessarily able to confidently address.

Incentives for Other Adult Providers to Replicate the LIFEsSpan Model

One consideration in replicating this program is how would other adult healthcare providers view incentives to replicate the LIFEsSpan model. As two large freestanding rehab providers, Toronto Rehab and Bloorview Kids Rehab share some unique characteristics which may have contributed to the success of the model. Some similar characteristics exist between these two organizations, which may or may not exist in other areas, such as:

- both are large freestanding teaching facilities with a focus on research excellence and innovations; there is a limited number of similar organizations
- both have a rehabilitation mandate, where as other regions may not have a freestanding adult rehab center or an organization with a primary rehabilitation mandate.
- Bloorview Kids Rehab is the only freestanding pediatric rehab hospital in the province.

In discussing factors that may provide incentives to other adult-focused organizations/services to replicate the LIFEsSpan transition model, participants highlighted such benefits as:

- Providers feel that their patients' needs are better met and a gap in services has been filled
- Providers appreciated the opportunities for cross education and collaboration
- Patients and families have expressed their appreciation for the service
- The initiative supports a mandate to be a leader in rehabilitation and potentially in research
- Potential for enhanced program funding through replication of the model
- Increased exposure for the organization locally, nationally and internationally
- Supports development of enhanced relationships with partnering organization(s)

From an overall system perspective, while there may be upfront costs to initiating a model similar to LIFEsSpan, investments to support continuous health management of individuals with life-long needs can have a clear incentive for Local Health Integration Networks by lessening the costs downstream for those who may need to access more costly emergency care services due to lack of coordinated services to manage ongoing health needs in the community.

From a pediatric provider perspective, there is also a clear incentive in taking part in a LIFEsSpan model; as described in the "Critical Milestones" section, this model arose out of a need in the pediatric sector to manage increasing pressures created by the return of former clients for services well into adulthood. Replicating the LIFEsSpan program, then, may serve a similar function of 'releasing the valve' of pressure on other pediatric providers, as it did for Bloorview Kids Rehab. There is potential that other pediatric providers may see the benefit of a LIFEsSpan type of model by facilitating patient flow through and maximize resource usage for the target populations while still ensuring that the needs of their graduating clients are met.

Through discussion with the stakeholders, it was identified that unless an organization is involved which shares similar characteristics to Toronto Rehab, it may be more challenging to engage the adult provider in a LIFEsSpan type of model. Although risk is shared equally between the adult and pediatric providers, the gains may be delayed for the adult provider while the impact on adult resources will be immediate. Nevertheless, although there were increased demands on adult resources, one of many successes came in obtaining additional funds as part of the development of the program.

Future replication of the current model should consider providers who share a similar culture, mission, values and characteristics with the recognition that the successes and rewards while many, may not come immediately. In particular, there is a need to consider how best to incent and support the adult provider who, in this model, bears the heavier load of service provision and resource utilization.

Other factors to consider in replicating the LIFEsSpan transition model included maximizing existing community resources; and considering a regional focus for the model.

Maximize Community Linkages

In exploring options for the replication of the LIFEsSpan transition model, some participants suggested a stronger focus on building linkages with existing community resources would be beneficial.

I think if I was to be doing the whole thing again, I would focus even more on the community, on the networking, on looking at the service providers that you are going to link with. Employment

support, the housing, the attendant care... make sure that they are aware of it there, you know, that... once the clinical team is in place, they develop more partnerships... try to steer it in that direction.

...if you even look at the basics of system navigation or linking people, one of the things...outlined is somewhere in a community, having a systems navigator, having somebody who can at least help link. See I do believe the systems are out there, but I do believe people don't know about them. And therefore developing a whole new parallel system, we both can't afford and it's not going to happen.

A Regional or Provincial Scope

A broader scope for the LIFEsSpan transition model, such as a regional or provincial model with feeder sites, was suggested by some participants and stakeholders, particularly when considering remote areas. Use of a broader scope was identified as an alternative which could support the principles of the LIFEsSpan model while still leveraging the expertise, resources and critical mass that were identified as being crucial. A regional model was also discussed as likely to be easier to replicate and more likely to have the key enablers in place to support development and implementation than relying on the current structure of LIFEsSpan.

I would take this model and I would make it province wide. It's not a LHIN based, it's a provincial, regional, at least a regional model, if not a provincial. And I would not segregate the populations that would be served. That anyone who needs to be transitioned, in a "Lifespan" way, can access the service and they can get it. And that, those services are um, cohesive and consolidated, they are not all over the place.

Stakeholders discussed the possibility of linking family health teams and children's health centres as one type of alternative model. One participant described a possible structure for a community-based model which did not necessarily require "growing" the current LIFEsSpan transition model:

G2 I think the other thing is I would look at a community based model... Where you would have an Anne Johnston type of link.

I Like a satellite...

G2 Yeah...And you would have them dotted in quadrants...And then it could be the triage clinic so if you're a student in York University and you happen to get a urinary tract infection you can go into a specialized clinic and get your coordinated care there. It doesn't have to have a full time physician, it shouldn't, it can have a good nurse practitioner, and then maybe once a year you come through the big assessment clinic. If money were no option that's how I would tackle it...I wouldn't grow it everywhere.

5.2 EXPANSION OF THE CURRENT LIFESPAN MODEL

Equity of Access

Perceived Needs are Greater than Available Services

Most participants, if not all, recommended the expansion of the LIFEsPan transition model to other population groups.

I think other disabilities should be included in LIFEsPan – definitely...because... if we try to justify why it's the two populations of CP and ABI, other than convenience, I don't think there is a real justification for it...right now it's inequitable. And should we be allowing clients from the community who...have already graduated from Bloorview and are banging on TRI doors saying: "Let me in"? Ideally, yes. I think it all comes down to funding. I think it's the major barrier right now it's the resources.

An Ethical Framework for Decision-Making

Staff who were interviewed expressed feelings of conflict at not being able to meet the needs of other populations. While feelings of internal conflict may be indicative of the success of the services, it also identifies a challenge in balancing equity of access with available resources. Given the likelihood of limited and/or incremental funding, it is recommended that an ethical framework for decision-making be developed and shared to support all staff.

...I think that's a challenge if you know something is successful, or you think it's going to be successful and life-changing, then it's hard to only offer it to a certain sector.

I think the comprehensive service at pediatrics is so wonderful but then to withdraw services at 18 without a plan is, I've heard people use the term "Unethical" or, I don't know what strong word to use, but...it's wrong...a lot of people have hidden behind the fact," well, it's not our mandate". Well, it's your mandate to pass kids on, you can't just, drop them, at that point in time.

Discussions with the analysis team and with stakeholders acknowledged that prioritization of population groups reflected the realities of limitations in funding and capacity. However, given the conflicts expressed, any expansion or replication of the LIFEsPan transition model should reference a framework for ethical decision-making. Communication of the populations targeted in an expansion or replication of the program would be based on this framework and may outline guiding principles such as to type of services provided, rationale and when other populations may be targeted in the future.

When discussing an ethical framework with stakeholders, high volume groups were identified as most likely targets for expansion with priority placed on those who also require more than basic medical follow up. The stakeholder group emphasized the need to focus on those requiring an interprofessional rehabilitative approach to address function and ongoing medical needs due to a childhood onset disease/disability. Furthermore, given that these feelings of conflict/guilt spanned across management and frontline clinician levels, a communication strategy to support staff in understanding how and why decisions are made may be beneficial.

Considerations in Planning for Expansion to Additional Populations

Should the LIFEsPan model be expanded to other populations, there is not much change required to the model itself; however, it is recommended that the funding, partnerships, and staffing complement and expertise are also expanded relative to the expected increase in volume and complexity of the new population(s). Re-evaluation of existing prioritization tools may also be warranted with increased numbers and complexity of patients.

A Transferable Model

Similar to discussions regarding replication, when considering to whom and how LIFEsSpan should consider expansion, most participants identified that the LIFEsSpan *model* itself would not require much change, but that the work completed to date should be leveraged.

Let's separate off "Lifeskills" as a model to "Lifeskills" as a process. Because I think you have to do that. I think the basic model is in good standing.

Participants identified that expansion to any other population would require a re-evaluation of factors such as: (1) funding; (2) staffing complement and expertise; (3) partnerships; and (4) program scope (e.g. catchment area and eligibility criteria).

Funding

The main challenge to expansion identified was funding. A common theme reflected was that funding enhancement would be required to consider expansion to another population group.

...from my perspective I think that expanding it would require more resources...either that, either that we just be spreading ourselves very, very thin. Which...would undermine the nature of the model, 'cause the transition would not be smooth and prompt...

... if you open up LIFEsSpan even to populations we are already serving to the general community, rather than direct transfer..., we would not be able to cope. I would not be able to cope...you would have no option, you would be so inundated so fast, you wouldn't be able to meet the needs of anybody and you wouldn't be doing anything well for anybody...

Partnerships

Because the LIFEsSpan model places great emphasis on a systems navigation role, identifying and building up appropriate partnerships for any new population was highlighted as a basic consideration in expansion to other populations. In particular, ensuring that the new partners in care are able to support the mission, vision and values of the LIFEsSpan model would be important.

You've got... some of the right players, but there are additional players, respirologists, neurologists who need to come into that setting... they're not bought in yet.

Staffing Complement and Expertise

There was recognition that the staffing complement may require shifting with introduction of new populations into the LIFEsSpan service delivery, depending on the needs of the new population.

...with the cardiac...you'd be looking at cardiologists, you'd be looking at maybe exercise therapists...the complement of professionals would have to be slightly different with the arthritis...maybe...rheumatologists. It could be more individuals that have orthotic needs or splinting needs, so a slightly different specialty.

In particular, participants emphasized the need to ensure that the right depth and breadth of expertise was available on the adult side.

I did a lot of work with people who have spina bifida... and [the LIFEsSpan model] would really-really work well. But I think that you'd have issues that are unique to that population such as bowel and bladder routines and stuff... you'd have to make sure the staff are aware and can address those things. Like here ...it's not that much of an issue but with a population like spina bifida it would be, and you'd have to have the appropriate staff to be able to address it.

...20 years ago... you didn't live long with Duchene's muscular dystrophy, now... [you could] live into your 30s and beyond. So a totally different ball game. And there isn't the expertise in the adult rehab settings, so I think that, that really needs some very unique and innovative approaches.

...the staff may need a broader depth of knowledge depending on the types of conditions that come through...being able to resource to other areas, to make the linkages.

Program Scope

Depending on which population is being considered for expansion, logistics such as eligibility criteria, prioritization tools and catchment area may need to be reviewed to maximize available funding. Although the current LIFEsSpan transition model and patient volumes support access for nearly all interested Bloorview patients with CP or ABIC; given limited resources, if LIFEsSpan were expanded, a review of triage/admission criteria is suggested to ensure that services are provided to those with the greatest needs for this transitional program.

Potential Populations for Future Expansion

Specific population groups suggested throughout the interviews and discussion with stakeholders included the following, in no particular order:

- Adults in the community with CP/ABIC who have not gone through LIFEsSpan
- Spina bifida and neuromuscular population
- Pediatric arthritis and musculoskeletal groups
- Childhood onset transplants group, particularly cardiac
- Pediatric oncology
- Pediatric stroke
- Respiratory (e.g. lung disease, cystic fibrosis)
- Complex medical, multiple diagnosis with long term health issues and possibly mental health issues
- New immigrants to Canada with childhood onset diseases/disability (e.g. spina bifida) who have never accessed pediatric services

6.0 LESSONS LEARNED: RECOMMENDATIONS FOR REPLICATION/EXPANSION OF THE LIFESPAN MODEL

The process evaluation of the LIFEsPAn transition model conducted by the GTA Rehab Network, sought to understand the development and implementation of the model in order to inform future replication and expansion opportunities. Several lessons can be learned from the successes and challenges of the current LIFEsPAn transition model.

- Ensure that there is support at all levels for the project, particularly at the senior management level.
- Commitment from all stakeholders is essential to success; this includes commitment to staffing, funding, space, and other supports. In particular, ensure that the success of the model becomes an organizational priority (e.g. on the strategic plan).
- A jointly appointed coordinator served as a bridge between the two organizations and facilitated both the development of the model as well as the development of trust.
- In order to benefit from a cross-appointed staffing model, find ways to mitigate the associated challenges such as ensuring that communication, documentation, scheduling and other processes are streamlined for efficiency.
- Develop tools to support mutual communication and understanding of how the collaboration will occur (e.g. through a memorandum of understanding). These tools will help build a sustainable foundation. However, leave room for flexibility as the collaboration evolves.
- Equity in contribution, risk and decision-making at all levels is essential to building a true collaborative model.
- Invest in team building and co-branding of the model.
- In developing the program, look for corresponding programs between the adult and pediatric populations; by leveraging existing expertise and resources the early development can be enhanced.
- Consult an ethical framework to guide decision-making and reference the framework in all communications with staff.
- Build in evaluation as much as possible. Setup clinical and organizational measurement tools.
- Maximize use of available staff and ensure that roles are clearly defined. Consider use of alternate staffing such as family/youth facilitators to fill roles that do not require expert training.
- Develop a common understanding of the definition of “rehab” and “complexity”
- Consider the extent to which existing internal services (e.g. AAC) may be able to support the LIFEsPAn model.
- Ensure that the model ultimately meets the local or regional needs of the population.

I think it's easy in hindsight to say you'd have done things differently but I think the secret in developing all of these things, is to deal with whatever comes up, and, and adjust accordingly. My strong suggestion would be not to come up with a blueprint. You can come up with guidelines, you can come up with principles, you can come up with objectives, but don't come up with a blueprint...because every community and every disability group will need slight variations on the theme.

7.0 CLOSING COMMENTS

This process evaluation sought to better understand the development and implementation of the LIFEspan transition model as they relate to future replication and/or expansion. The model was found to have met its original goal though the long term outcomes (outside the scope of this evaluation) are still being studied. Critical milestones, enablers, and challenges were identified which will facilitate future development of similar transition models.

The LIFEspan transition model is transferable and can meet the goal of supporting a coordinated transfer of care to adult services, as developed by Bloorview Kids Rehab and Toronto Rehab. Replicating the current model in other regions will require consideration of the availability of both pediatric and adult organizations. There may be a limitation in how many organizations are similar enough to support this transition model, however providers do not necessarily need to be limited to free standing rehab organizations as per implementation of the current LIFEspan transition model.

Replication of the model can likely occur with some variation. The essential components to consider are enhanced community linkages, an adult provider ‘home base,’ and a regional scope. Furthermore, if replicating the model, consideration should be given to incentives for adult healthcare provider organizations, available critical mass, resources and expertise for the targeted populations.

Expansion of the LIFEspan model to other populations is possible without much change to the model itself; however, it is recommended that the funding, partnerships, and staffing complement and expertise are also expanded relative to the expected increase in volume and complexity of the new population(s). Furthermore, although the current model and patient volumes support access for nearly all interested Bloorview patients with CP or ABIC, given limited resources, if the LIFEspan transition model is expanded, a review of triage/admission criteria is suggested to ensure that services are provided to those with the greatest needs for this transitional program.

APPENDICES

Appendix 1: The LIFEsSpan Transition Model

Source: LIFEsSpan. (2007). *Transitions to adult services project business plan proposal for: LIFEsSpan services for individuals with childhood onset disabilities.*

The Lifespan partnership initiative shares the philosophical foundations of the vision and mission of both Bloorview Kids Rehab and Toronto Rehab: ***creating a leading-edge service that respects and builds upon the strengths and uniqueness of our clients, their families and support networks, and that strives to coordinate services and facilitate access, both internal and external to the organizations, in order to provide the best possible care.***

The Lifespan Model for childhood onset disability can be described in five phases. The model incorporates services in both the pediatric setting (e.g., Bloorview Kids Rehab), the adult setting (e.g., Toronto Rehab) and across the lifespan of the client, beginning from onset of the disability. The five phases are described below and depicted in Figure 1. The role of the Nurse Practitioner (NP) is a central and key component of the service with the goal being that the NP practices to their full scope of practice with a focus on specialization in managing the needs of persons with Childhood Onset Disabilities. The NP will work with the family physicians in managing the primary health needs of these populations as well as a broad spectrum of specialists. The NP will be a jointly appointed position (working in both Bloorview and Toronto Rehab) to maximize coordination, communication, and continuity, and to provide a familiar face across the transition.

1. Growing Up Ready / Preparation for Transfer at Bloorview

The *Growing Up Ready* Framework is a comprehensive model designed to provide guidelines for the development of life skills and self-efficacy beginning at early ages. As clients near the age/developmental stage at which they will transition from pediatric rehab services to adult services, clients will be seen by an interdisciplinary Preparation for Transfer Team in the Child Development program (currently RN, OT, SW and Youth Facilitator) or by their expert team for other diagnostic groups, to address outstanding issues and formally prepare the client and family for transfer. This phase will likely occur over a period of 2-3 years when clients are 15-18 years of age. The families will be informed of the partnership service with Toronto Rehab and the Lifespan Service model for adults with chronic disabilities of childhood onset at Toronto Rehab.

2. Transfer Clinic at Bloorview

This step involves a comprehensive needs assessment by a Nurse Practitioner (jointly appointed at Bloorview and at Toronto Rehab) or the Expert team. In collaboration with the Preparation for Transfer team, and other medical specialists the NP or Expert Team will facilitate appropriate referrals within Bloorview Kids Rehab, other pediatric providers, or adult providers as appropriate to address outstanding issues. They will identify ongoing issues moving forward (i.e., identify what resources and services are required upon transition). The transfer of care to Toronto Rehab will be discussed with the client/family and a referral form will be completed.

3. Referral and Triage (both centres involved, primarily an administrative step)

Referral is received at Toronto Rehab by a Service Coordinator (SC). The SC will contact the NP, the expert team leader and other Bloorview Kids Rehab team members to discuss client needs. This may be in person, or via phone. If the client's needs are complex, a team meeting may be recommended and the client/family may be invited to (or may select to) attend. With this collaboration, the SC will determine the disciplines required for initial Toronto Rehab team assessment. The SC will contact the client/family to inform them of their admission

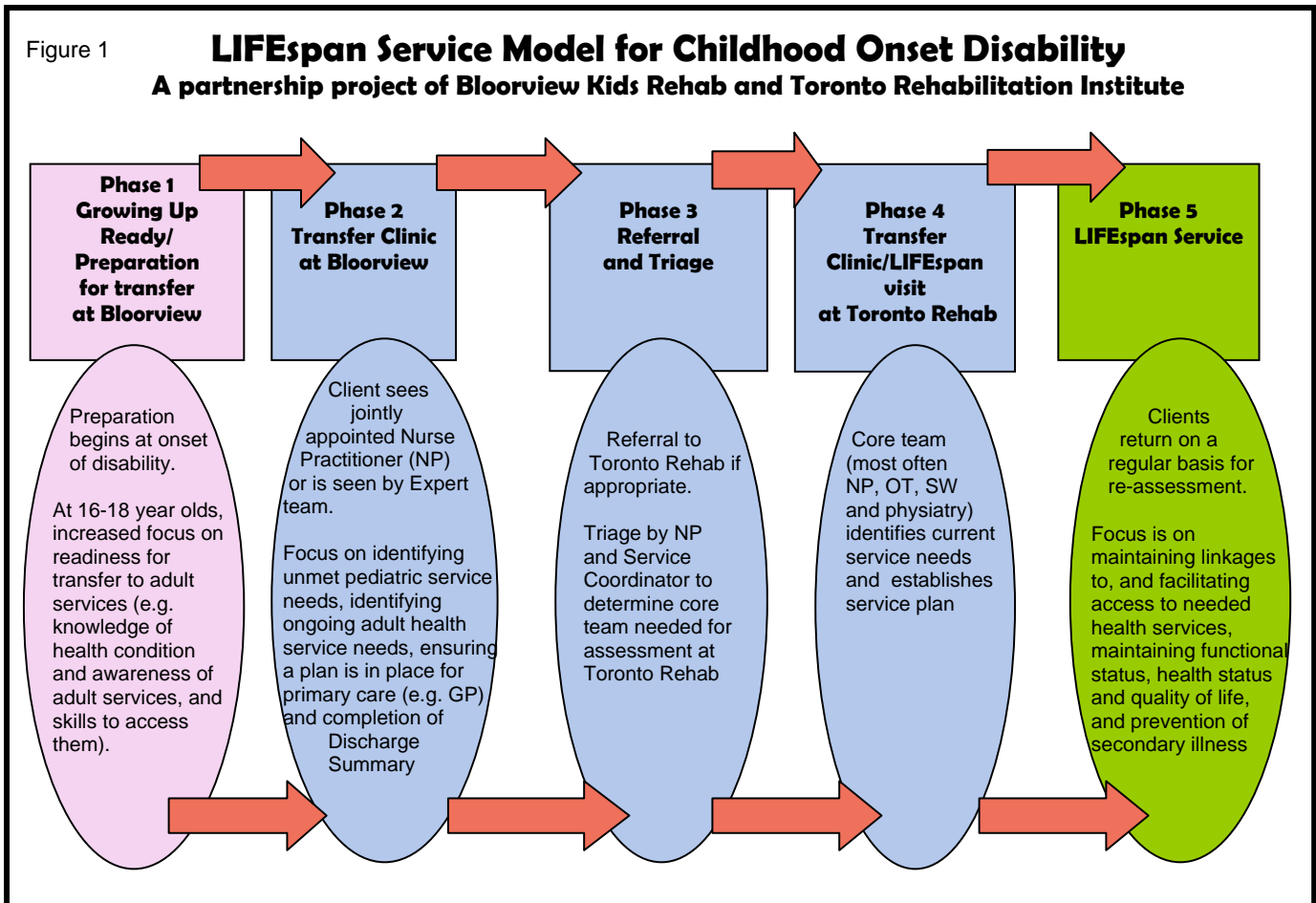
and will gather any additional information as required. The initial assessment appointments will be coordinated with assistance of a program assistant.

4. Transfer/LIFEsSpan Clinic at Toronto Rehab

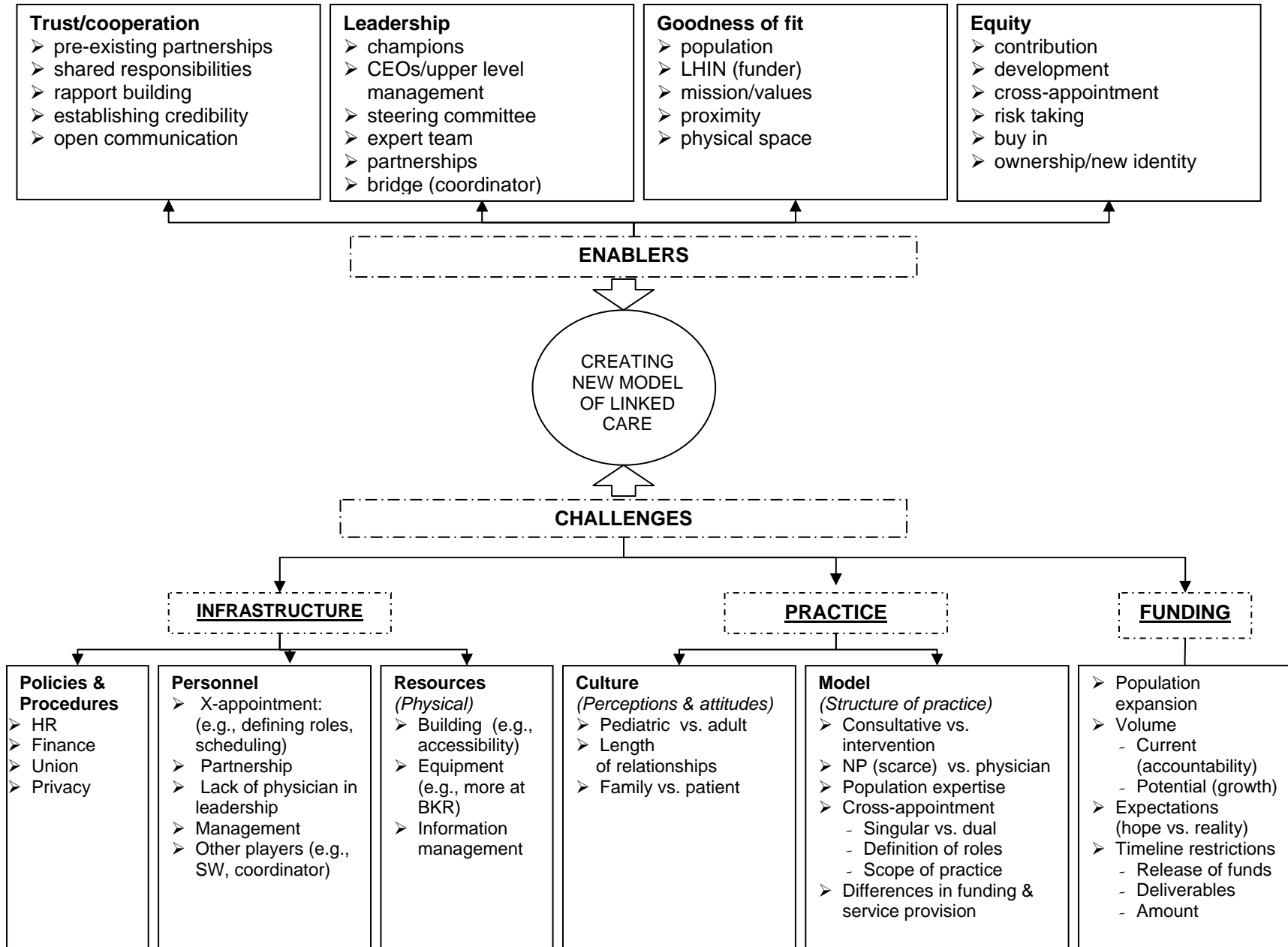
The client will have their first visit at Toronto Rehab. The NP, with a core team of OT, SW and Physiatry and any other professionals identified by the SC as necessary for initial assessment, will see the client at this visit. A youth facilitator will also see the client as a member of the interdisciplinary team. Timing of this initial Toronto Rehab visit may be dependent on immediacy of need, availability of resources, and client choice, but ideally should occur no greater than 12 weeks following the transfer assessment at Bloorview Kids Rehab. The team will conduct their assessment and make any additional referrals (within and external to Toronto Rehab) the team determines to be appropriate. A team client/family conference is arranged following the assessments (same day if possible) to discuss goals and plan. The client may or may not require direct intervention/treatment at Toronto Rehab.

5. LIFEsSpan Service Return Visit and Annual Review at LIFEsSpan Service at Toronto Rehab

A follow-up visit will be arranged six months after the initial assessment with a review by the NP and other team members if deemed appropriate at initial assessment, or due to change in client needs/function. Clients will return annually at minimum (more frequent returns may be recommended for some clients). Prior to the return assessment, the NP will contact the client/family via telephone to determine the appropriate team members required for the assessment.



Appendix 2: Diagram of Enablers and Challenges



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