# Caregiver Framework for Children with Medical Complexity Phase 3 Evaluation: Final Report

Submitted to:
Cindy Bruce-Barrett, Hospital for Sick Children


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A. Paul Williams, PhD.        Principal, Balance of Care Research and Evaluation Group

Karen Spalding, RN, PhD.    Co-Principal

Allie Peckham              Research Associate
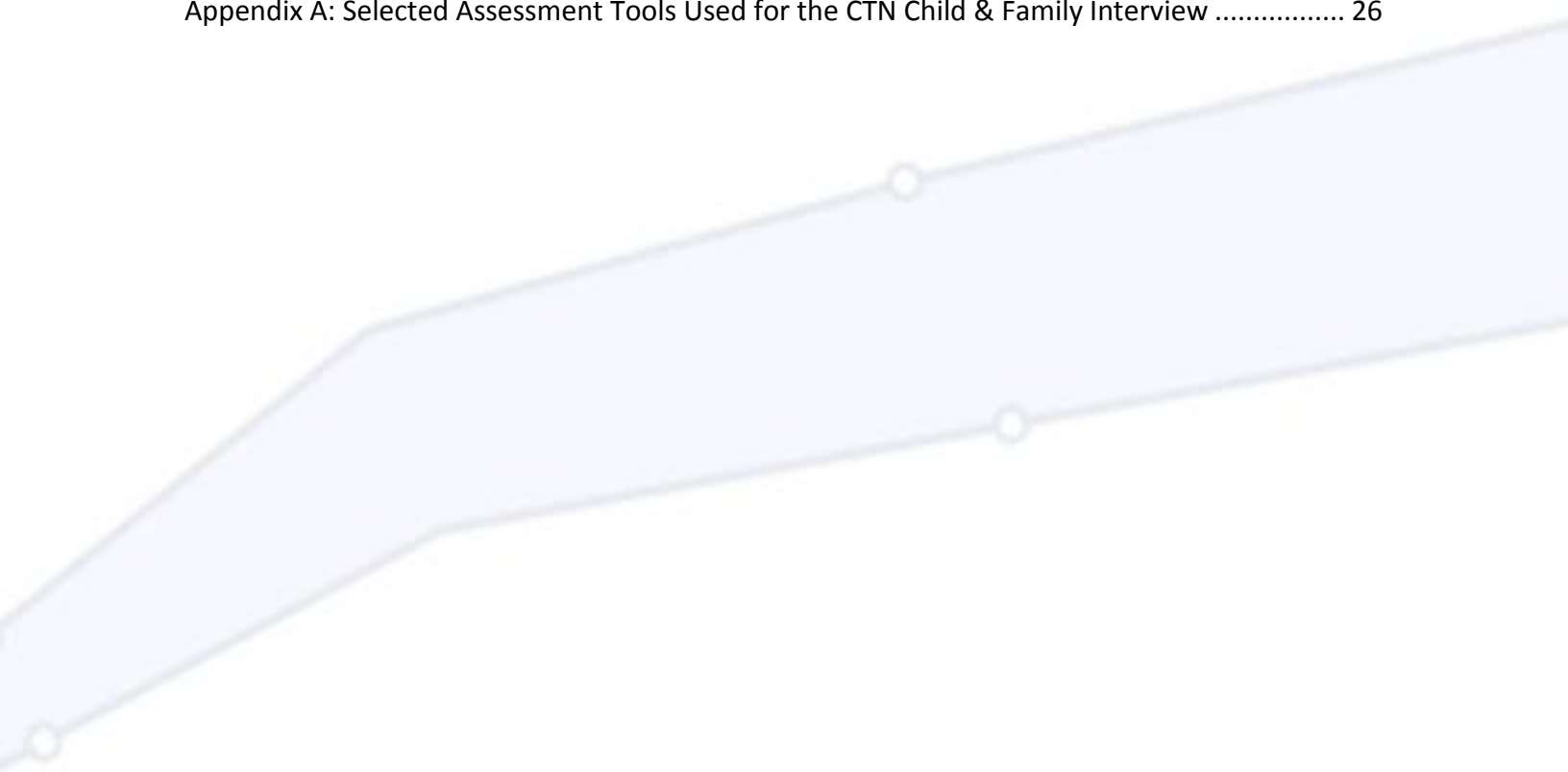
David Rudoler             Research Associate

Tommy Tam               Research Associate

Jillian Watkins            Research Associate

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## Table of Contents

## Acknowledgements

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## Executive Summary

### 1.0 Introduction

The Caregiver Framework (CF) for Children with Medical Complexity (CMC) provides a flexible mix of health and social supports, as well as ongoing counselling and care management, to family caregivers of CMC judged to be "at risk" as a result of their caregiving activities.  It is led by the Hospital for Sick Children (SickKids) in partnership with the Toronto Community Care Access Centre (TC CCAC) and Holland Bloorview Kids Rehabilitation Hospital (Holland Bloorview).  It is funded by the Toronto Central Local Health Integration Network (TC LHIN).

Drawing on funds averaging about $3,500 per caregiver, per year, specially trained care managers (Key Workers) engage "at risk" caregivers in a dynamic process of problem-identification and problem-solving, leading to the co-creation of individualized support packages.

### 2.0 What We Did

Our earlier *Formative Evaluation* asked "if" the CF should continue; in this evaluation of the CF's third phase (CFP3) we focused on "how" it should evolve to maximize value for caregivers, CMC and other stakeholders.

### 2.1 Review of Joint Working and Key Worker Models

We conducted a targeted review of the international literature on "joint working" between providers of services for children with complex needs.  Because such children typically require multiple services from multiple providers across health and social care sectors, "joint working" or collaborative team approaches are widely seen to promote better coordination and more appropriate care.  We also interviewed senior leaders of the Children's Treatment Network (CTN) of Simcoe York; CTN had been identified by key informants in the earlier *Formative Evaluation* as an innovative model of care for children with complex needs and their caregivers.

### 2.2 Follow-up Key Informant Interviews with CF Staff and Key Workers

We conducted in-depth, qualitative interviews with CF project staff and Key Workers to understand, from their "front-line" perspectives, how the CF had evolved, and where it should aim to go in the future.

### 2.3 Analysis of Caregiver Assessment and Care Plan Data

We received and analyzed assessment and care plan data for 42 CFP3 participants, including 41 caregivers and 42 CMC (two were siblings).  Our analysis focused on goal identification and attainment.

### 2.4 Caregiver Interviews

We conducted semi-structured, in depth, qualitative interviews lasting about 30 minutes with a number of caregivers. We asked about their overall experiences with the CFP3, and about how it had impacted on caregivers and families.

## 3.0 What We Found

### 3.1 Review of Joint Working and Key Worker Models

Children with multiple chronic needs and their families can face formidable challenges accessing and coordinating needed services and supports on their own. Such challenges have led many researchers and providers to look to collaborative team-based approaches or models of "joint working" which span a continuum that includes multi-disciplinary, inter-disciplinary and trans-disciplinary teams. While valuable in and of itself, the value of the Key Worker role can be magnified when they lead, or are embedded within, collaborative teams or other forms of "joint working."

### Children's Treatment Network (CTN) of Simcoe York

The Children's Treatment Network (CTN) of Simcoe York has been identified as an exemplary local model of care for children with ongoing complex needs and their caregivers. Among its key characteristics, CTN uses a common assessment, shared client record, and single plan of care which establish the operational nexus for inter-professional and inter-organizational team focused on the needs of the child and family. Joint working is encouraged through mechanisms including financial incentives; accountability agreements; technology; and regular meetings and training sessions. Evaluations have shown uniformly positive results.

### 3.2 Follow-Up Key Informant Interviews with CF Staff and Key Workers

CF staff and Key Workers highly rated the CF's performance during its third phase. They observed that:

- **The CFP3 had seen a positive shift toward longer-term goal-setting.** This facilitated useful dialogue between caregivers and Key Workers about what was needed to sustain the caregiver, as well as the CMC and family over the longer term
- **A new administrative review process worked well.** Because it placed budget allocation decisions in the hands of an administrative team (instead of the Key Worker), the new process had allowed Key Worker/caregiver conversations to focus more on goals.

Some challenges remained:

- **Not all caregivers embraced goal-setting.** Those who had participated in earlier phases of the CF were more difficult to engage
- **Some caregivers found the assessment and goal-setting process taxing.** Key Workers noted that the process often required multiple visits

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- **CF staff and Key Workers faced time constraints.** CF staff and Key Workers said there hadn't been sufficient time in Phase 3 to complete assessments and engage in goal-setting.

Key informants offered a number of suggestions for improving CF's performance:
- **Provide Key Workers with ongoing training.** Key Workers and CF staff identified that additional and ongoing training around problem-solving and goal-setting would enhance the CF's performance
- **Clarify administrative guidelines around money.** Key Workers said that clearer guidelines around what money families are eligible for and what they are likely to receive would allow them to concentrate more on setting and attaining goals
- **Shorten the front-end assessment.** Currently, assessments collect medical information about the child which is also collected elsewhere; duplication could be reduced by using a common electronic record
- **Purposefully design the process so that it takes place over two to three visits**. Caregivers and Key Workers suggested that it would be beneficial to extend the goal-setting process over multiple visits to develop a fuller picture of what the family needs
- **Consider that not all care plans may require dollars.** Key Workers felt that families the funding component of the CF could be more closely tied to economic means
- **Better integrate the CF within the ICCM and with other providers.** CF staff and key Workers suggested that the CF's success could be strengthened by bringing together other organizations and providers who are also caring for the same children and families.

### 3.3 Analysis of Caregiver Assessment and Care Plan Data
A range of goals, co-created by caregivers and Key Workers, are recorded in the assessments.
- **Some goals still focused on the (mostly medical) needs of the CMC**. For example, incontinence supplies emerged as a significant issue for some families: "Mother's largest concern is the financial burden of the diapers and the wipes"
- **Many goals were caregiver-focused.** Key Workers said that they encouraged caregivers to sort through their own physical, social and mental needs and to consider what was required to maintain their resilience and capacity
- **Other goals looked more broadly toward maintaining the integrity of the family.** Caregivers, Key Workers and CF staff repeatedly commented on the high levels of stress experienced by many families caring for CMC; family breakup was a too-frequent outcome. Not surprisingly, many of the goals recorded in the assessments aimed at sustaining families.

The health care needs of CMC still figure prominently in care plans. However, supports for caregivers were diverse, stretching well beyond health care to include:
- **Self-care** (including gym memberships, counseling and yoga)

- **In-home supports and respite** (including coverage at night and assistance with household chores)
- **Connections to community supports** (including respite agencies, church resources, and organizations like Plan Toronto which provide specialized services for families)
- **Health care** (including physician, dentist and acupuncture services)
- **Home modifications and equipment** (such as ceiling lifts, a back-up generator, and accessible housing)
- **Transportation** (such as obtaining a modified vehicle, applying for funding for vehicle modifications, and purchasing a Metropass)
- **Employment supports** (including support for improving a caregiver's resume and engaging in volunteer work to identify potential careers).

## 3.4 Caregiver Interviews

Caregivers reported high levels of satisfaction with, and support for the CF. Caregivers interviewed had nothing but praise for this CF which they described as "amazing", "wonderful", "fantastic" and "positive". They noted:

- **The CF's financial support was vital.** Caregivers emphasized that the CF provided needed care, respite and a sense of peace; the funding helped to relieve stress from financial concerns
- **The personal connections developed with Key Workers were very valuable.** Caregivers said that the best aspect of the CF was the connection with the Key Worker who went above and beyond to understand and support caregivers.

As a result of the CF:

- **Caregivers said they were more able to continue to care.** In the short-term, the CF offers "peace of mind", emotional support and much needed respite to recharge and refresh caregivers. In the long-term, it helps to improve their confidence and resilience
- **Caregivers had new opportunities to connect with other families.** The CF helped some caregivers to build networks of mutual-support and knowledge transfer (e.g., sharing information about doctors, specialists and medications)
- **Caregivers were better able to connect with needed formal services.** As one caregiver shared, it "open[ed] her eyes" to the different services available and feeling more connected.

Caregivers made the following suggestions:

- **Conduct assessments more frequently.** Because CMC are often medically unstable and their needs can change rapidly, more frequent assessments (e.g., semi-annually or every 9 months) can ensure more appropriate and effective care for CMC and families
- **Consider different funding methods.** One caregiver suggested that funds be provided in the form of a credit or gift card to make management and tracking easier.

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## 4.0 Conclusions

While caregiver burden and stress are often conceptualized primarily or solely as a function of the needs of the CMC, the results of this evaluation clarify that caregiver burden and stress also result from the sheer effort needed to navigate "non-systems" of unconnected services and providers, each with varying eligibility requirements, assessments, benefits and out-of-pocket costs.

This is where the CF generates so much value.  All stakeholders agree that by having specially trained Key Workers engage "at risk" caregivers to identify problems, create solutions, and connect with needed services and supports across different providers and sectors, the caregiver role is validated and reinforced, the family unit is strengthened, and CMC are more likely to get the supports they need to continue to live at home with less likelihood of "default" to hospital and residential care.

Our previous *Formative Evaluation* demonstrated strong support for the continuation and expansion of the CF; the current evaluation provides insight into "how" the CF can continue to evolve to maximize value for CMC, caregivers, and other stakeholders.  In summary, we observed that:

- **CF staff, Key Workers and caregivers continued to be strong supporters and advocates for the CF.**  CF staff and Key Workers highly rated the performance of the CFP3; caregivers described the CF and Key Workers as "amazing" and "wonderful"
- **Caregivers valued the financial assistance provided by the CF.**  Caregivers said that the money goes a long way to addressing immediate care needs and allowing them to think about what they need to stay healthy and resilient over the longer term
- **All stakeholders applauded the CF's shift toward goal setting.**  One caregiver recalled how the process had "open[ed] her eyes" to the different services available.  CF staff and Key Workers said this shift catalyzed more meaningful dialogues between caregivers and Key Workers; it presented new opportunities for Key Workers to actively engage with caregivers, establish trust and develop personal relationships
- **In setting future goals, more light was shed on caregiver needs.**  Key Workers used goal setting as an opportunity to encourage caregivers to sort through their own physical, social and mental needs and to consider what was required to maintain their resilience and capacity
- **The administrative review process, which shifted budget allocations away from Key Workers, strengthened the goal-setting process.**  in addition to leading to greater consistency, this often improved relationships with caregivers, and allowed for more thinking about the future
- **There are opportunities to further improve the CF's performance**.  Key informants suggested that the CF be more closely integrated with the Integrated Complex Care Model (ICCM) through mechanisms including a common care record, and with other providers through team approaches.

## 5.0 Recommendations

We offer three sets of recommendations to guide the ongoing development of the CF, emphasizing, once again, that it continues to draw strong supported from all stakeholders.

### 5.1 Continue to Strengthen the CF

Our first set of recommendations aims to improve the performance of the CF without requiring any major changes to its current structure or direction.

- **5.1.1 Provide planned opportunities for learning.** CF staff and Key Workers suggested, and we recommend, that CF personnel engage in regular training and professional development opportunities particularly around the goal-setting process

- **5.1.2 Consider "spreading out" the goal-setting process.** Key Workers suggested, and we recommend, that the goal-setting process be spread over two or three visits during the course of each year

- **5.1.3 Augment the administrative review process.** Clarify the administrative criteria used to make decisions about how much caregivers are eligible for and how much they actually receive; in addition to improving transparency, this would relieve Key Workers of the need to try to explain how decisions had been made

- **5.1.4 Aim to assess outcomes.** Our evaluation documents continuing strong support for the CF; however, we have not yet been able to demonstrate hard outcomes. A good first step would be to elaborate and pilot a set of qualitative and quantitative outcome measures, possibly linked to the ongoing development of the ICCM scorecard.

### 5.2 Encourage Collaboration and Joint Working

Our second set of recommendations aims to import mechanisms, separately or in combination, which promote collaboration and "joint working" within and beyond the CF.

- **5.2.1 Position Key Workers to work with teams.** Key Workers suggested, and we recommend, that stronger linkages be forged between the CF and other programs and providers also serving CMC and caregivers such as the ICCM, other home and community care providers, rehabilitation, mental health, primary care, and school boards; such linkages can be operationalized through consultative teams whose membership and focus would adjust to the changing needs of the CMC and caregiver

- **5.2.2 Establish electronic care plans accessible to providers and caregivers.** Key Workers suggested that electronic records shared with other programs and providers involved in the care of their clients could improve the continuity and coordination of care and promote better follow-up; making these records accessible to families would empower them to become more active partners in care

- **5.2.3 Introduce technology-enabled virtual rounds with caregiver participation.** We recommend that virtual rounds be initiated not only to facilitate joint working among providers, but to promote greater participation of caregivers and families in decision-making.

### 5.3 Build Toward a Network

Our third set of recommendations looks to the future evolution of the CF as the nucleus for a sustainable network which would explicitly situate the caregiver and CMC within a single "unit of care."

- **5.3.1 Use financial incentives.**  We recommend that the CF consider using some of its budget resources to bring more partners to the table; we further recommend that the TC LHIN consider enhancing the CF budget to enable it to act as the nucleus for an expanding network
- **5.3.2 Establish accountability agreements.**  Accountability agreements can clarify the roles and responsibilities of partners, and specify what families can expect and what is expected of them.  Even prior to establishing a formal network, the CF can elaborate accountability agreements with its current partners
- **5.3.3 Engage in regular partner meetings.**  During its third phase, the CF instituted, with considerable success, an administrative working group to review care plans and allocate resources.  We think that the mandate and membership of this working group could be expanded as the foundation for an emerging network.

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## Caregiver Framework for Children with Medical Complexity Phase 3 Evaluation: Final Report

### 1.0 Introduction

The Caregiver Framework (CF) for Children with Medical Complexity (CMC) is led by the Hospital for Sick Children (SickKids) in partnership with the Toronto Community Care Access Centre (TC CCAC) and Holland Bloorview Kids Rehabilitation Hospital (Holland Bloorview). It is funded by the Toronto Central Local Health Integration Network (TC LHIN).

Initiated in October, 2011, the CF provides a flexible mix of health and social supports, as well as ongoing counselling and care management, to family caregivers of CMC judged to be "at risk" as a result of their caregiving activities.

CMC are defined as children experiencing "medical fragility, chronicity, and complexity of health needs that leave the child vulnerable to multiple hospitalizations, unplanned readmissions and avoidable emergency room visits."

"At risk" caregivers are those "under stress" due to "the degree and/or intensity of caregiver effort in meeting the needs of the child; the physical, emotional, social or financial impact of meeting the needs of the child; or the collateral physical, emotional, social, or financial impact on the family as a whole."

Drawing on funds averaging about $3,500 per caregiver, per year, specially trained care managers (Key Workers) engage caregivers in a dynamic process of problem-identification and problem-solving, leading to the co-creation of individualized caregiver support packages.

The *Final Report of the Formative Evaluation (2013)*[1] concluded that in addition to addressing short-term needs and managing crisis, the CF, in its first two years, had generated longer-term value. As a result of the CF:

- Caregivers said they were less nervous or stressed; more confident about their ability to continue to care for CMC; more in control of their lives; more able to attend to the needs of other family members; and more confident about knowing where to go to find help when they needed it

- Key Workers reported that they had "new tools" for engaging with caregivers and building trust; identifying and addressing problems proactively; and avoiding crisis

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[1] Williams, A.P., Spalding, K., Peckham, A., Rudoler, D.,Salib, D., Tam, T., & Watkins, J. (2013). Caregiver Framework for Children with Medical Complexity: Formative Evaluation. Final Report.

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- CF staff and other stakeholders observed that the CF offers considerable long-term potential to sustain caregivers, while strengthening linkages between providers and contributing toward system integration.

Stakeholders strongly recommended the CF's continuation and expansion.  Other recommendations included a review and possible broadening of eligibility/selection criteria to engage more caregivers earlier on; continued emphasis on "supported self-management" where caregivers' decisions are assisted by professional Key Workers; and establishment of an accountability framework emphasizing the identification and attainment of personalized goals.

Funding for the CF was subsequently extended into a third year [CF Phase 3 (CFP3)]. Building on its success and informed by the recommendations of the *Formative Evaluation*, the CFP3 aimed to:
- Expand numbers of caregivers and families served through retention of some or all current participants and recruitment of new participants
- Clarify eligibility/selection criteria to ensure transparency, consistency and fairness for caregivers and children, and the best use of available resources
- Continue to develop a project infrastructure informed by best practices
- Identify and evaluate clear goals.

The *Balance of Care (BoC) Research and Evaluation Group*, based at the University of Toronto, was commissioned in October, 2013, to conduct the CFP3 evaluation; the *Group* had conducted the CF's earlier *Formative Evaluation*.  It had also evaluated a sister initiative, the *Caregiver Support Project* administered by the Alzheimer Society of Toronto, funded by the TC LHIN, which similarly uses a "supported self-management" approach to assist "at risk" caregivers of high needs older persons at the point of losing independence and requiring residential long-term care (LTC)[1].

In this report we begin by detailing the data and methods used in our CFP3 evaluation and then present key findings.  We subsequently offer recommendations to continue to strengthen the CF going forward.

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[1] Williams, A.P., Peckham, A., Rudoler, D., Tam, T., & Watkins, J. (2013). Caregiver Support Project: Formative Evaluation, Final Report. Accessed on-line at http://www.alzheimertoronto.org/documents/evaluations/ csp_evaluation_report_2013.pdf

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## 2.0 What We Did

In the earlier *Formative Evaluation* we asked "if" the CF should continue; in the CFP3 evaluation we focus on "how" it should evolve to maximize value for caregivers, CMC and other stakeholders.

In doing this, we turned to the literature and considered the experiences of an Ontario-based care network for children with complex needs and their caregivers; examined assessment and care plan data from CFP3; and spoke with those most directly involved in the project: CF staff, Key Workers, and caregivers.

## 2.1 Review of Joint Working and Key Worker Models

We began with a targeted review of the expanding international literature on "joint working" between providers of services for children with complex needs with the aim of identifying best practices and insights to inform the continuing evolution of the CF.  Because such children typically require multiple services from multiple providers across health and social care sectors, "joint working" or collaborative team approaches are widely seen to promote better coordination, and more appropriate care.  This literature clarifies that Key Workers may be embedded in or lead multi-disciplinary[1,2], inter-disciplinary[3,4,5] and trans-disciplinary teams[6].

We then interviewed 2 senior leaders of the Children's Treatment Network (CTN) of Simcoe York; CTN had been identified by key informants in the earlier *Formative Evaluation* as an innovative integrating model of care for children with complex needs and their caregivers.  CTN conducts an inter-disciplinary assessment of child and caregiver needs (including health and extending to social supports, education and beyond); develops a single plan of care; and uses an electronic care record.  In our interviews we asked about these mechanisms and the extent

[1] Morton, R., Billings, K., Hankinson, J., Hart, D., Nicholson, J., Rowlands, A., Saunders, R., & Walter, A. (2003). Individual responsibilities in multidisciplinary working. *Current Paediatrics*, 13(1), 23–29.

[2] Rahi, J. S., Manaras, I., Tuomainen, H., & Hundt, G. L. (2004). Meeting the needs of parents around the time of diagnosis of disability among their children: evaluation of a novel program for information, support, and liaison by key workers. *Pediatrics*, 114(4), e477–482.

[3] Carter, B., Cummings, J., & Cooper, L. (2007). An exploration of best practice in multi-agency working and the experiences of families of children with complex health needs. What works well and what needs to be done to improve practice for the future? *Journal of clinical nursing*, 16(3), 527–539.

[4] Greco, V., Sloper, P., Webb, R. & Beecham, J. (2006). Key worker services for disabled children: the views of staff, Health and Social Care in the Community, 14 (6), 445-52.

[5] Abbott, D., Townsley, R., & Watson, D. (2005). Multi-agency working in services for disabled children: what impact does it have on professionals? *Health & social care in the community*, 13(2), 155–163.

[6] Alston, M., Barber, N., Mlcek, S., & Witney-Soanes, K. (2007). Draft Interim Invest to Grown Evaluation Report. Wagga Wagga: Charles Sturt University.

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to which lessons learned by CTN might be helpful to the CF.  We also reviewed a number of published articles documenting the CTN and its outcomes[1,2,3,4].

## 2.2 Follow-up Key Informant Interviews with CF Staff and Key Workers

We conducted 6 in-depth, qualitative interviews with CF project staff and Key Workers to understand, from their "front-line" perspectives, how the CF had evolved, and where it should aim to go in the future.

Interviews were conducted by telephone or in-person by pairs of evaluation team members who took detailed field notes and subsequently cross-checked notes for accuracy.  Interviews averaged about 30 minutes in length; they took place between January and March, 2014.

Key informants were asked combinations of the following questions:
- How has the CF developed/changed/adapted over the last year?
- Which components of the CF seem to produce the most enduring benefits?
- What's needed to continue to move forward?

## 2.3 Analysis of Caregiver Assessment and Care Plan Data

We received assessment and care plan data for 42 CFP3 participants, including 41 caregivers and 42 CMC (two were siblings), in April, 2014.  These assessments describe the characteristics and needs of CMC and caregivers including the medical, functional, and behavioural status of the CMC; informal caregiver supports; and overall family functioning.

Since we had presented assessment data describing the characteristics of CMC and caregivers in the report of our earlier *Formative Evaluation*, and since only a minority of CMC and caregivers were new to CFP3, we concentrated our analysis on goal identification and attainment.

The assessment and care plan data were transmitted to the evaluation team via a hand-delivered encrypted data key only after CF staff had stripped them of all personal identifiers.

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[1] Thurston, S., Paul., L., Ye, C., Loney, P., Browne, D., Browne, G., Wong, M., Thabane, L., & Rosenbaum, P. (2010). Clinical study. System integration and its influence on the quality of life of children with complex needs. International Journal of Pediatrics. Vol 2010. 1-12. http://www.hindawi.com/journals/ijped/2010/570209/cta/

[2] Thurston, S., Paul, L., Loney, P., Wong, M., & Browne, G. (2010). Clinical study. The quality of life of a multidiagnosis group of special needs children: Associations and Costs. International Journal of Pediatrics. Vol 2010. 1-13. http://www.hindawi.com/journals/ijped/2010/940101/cta/

[3] Thurston, S., Paul, L., Ye, C., Loney, P., Browne, G., Thabane, L., & Rosenbaum, P. (2010). Interactions among ecological factors that explain the psychosocial quality of life of children with complex needs. International Journal of Pediatrics. Vol 2010. 1-10 http://www.hindawi.com/journals/ijped/2010/404687/cta/

[4] Ye, C., Browne, G., Grdisa, V., Beyene, J., & Thabane, L. (2012). Measuring the degree of integration for an integrated service network. International Journal of Integrated Care. 12, 1-15. http://www.ijic.org/index.php/ijic/article/viewArticle/835/1783

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To further enhance security, all individual assessments were password protected; they are stored on a password protected computer in a locked office accessible only to the evaluation team.

## 2.4 Caregiver Interviews

During the earlier *Formative Evaluation*, we distributed a caregiver survey; however, response was low, reflecting caregivers' heavy workloads and high levels of stress.

For the CFP3 evaluation, we again attempted to hear caregivers' voices by offering them the opportunity to participate in a telephone interview at a time of their choosing. To minimize any real or perceived risk to privacy, the evaluation team was not given caregiver names or contact information. Instead, CF staff provided a short description of the evaluation and an invitation to participate; they were asked to contact the evaluation team directly if they wished to be interviewed. However, once again, response was limited; only 4 caregivers contacted the evaluation team to be interviewed.

Nevertheless, we conducted semi-structured, in depth interviews lasting about 30 minutes with each responding caregiver. Interviews were conducted by telephone by pairs of evaluation team members who took detailed notes and cross-checked notes for accuracy. Interviews took place between January and March 2014.

During these interviews we asked:
- What is your overall experience with the caregiver support initiative?
  - Has the caregiver initiative met your needs?
  - What was best/worst?
  - What, if anything, would you change?

- How has the caregiver support initiative impacted on you and your family?
  - Has it improved your ability to continue to care over the short-term; over the long-term?
  - Do you feel you are more connected with yours or other families?
  - Do you feel you are more connected with formal service providers?

As it turned out, a number of caregivers opted to provide feedback to us indirectly via their Key Workers; we have included this feedback in our analysis.

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## 3.0 What We Found

### 3.1 Review of Joint Working and Key Worker Models

#### 3.1.1 Models of "Joint Working"

The *Formative Evaluation* observed that Key Workers play a pivotal role in connecting CMC and caregivers to a range of formal providers and services. We turned to the international literature to add depth to this observation.

The results of our targeted review emphasize the reality, well documented in the *Formative Evaluation,* that children with multiple chronic needs and their families can face formidable challenges accessing and coordinating needed services and supports on their own[1,2]. A population study found that families of children with cerebral palsy required an average of 7 different services from different providers[3]; recall that the 53 CMC in the CF Phase 2 averaged 7 different diagnosed medical conditions; one lived with 14 medical conditions. As a result they required care from an average of 7, and up to 14 different physicians (both generalists and specialists); this number does not consider non-medical services and providers also required by CMC and families (e.g., rehabilitation, social work, personal support, education).

Such challenges have led many researchers and providers to look from service-by-service approaches which become increasingly difficult to manage as numbers of services and providers rise, to more collaborative team-based approaches or models of "joint working." In this connection, the literature describes a continuum that includes multi-disciplinary, inter-disciplinary and trans-disciplinary joint working[4,5] (see Figure 1).

- Multi-disciplinary working occurs when individual professionals work within a single agency. An example is when a health visitor, hospital consultant and speech and language therapist might work together within a health agency to introduce tube feeding for a child with complex needs

- Inter-disciplinary working is defined as individual professionals from different agencies and possibly sectors assessing the needs of the children and families separately, but

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[1] Beattie, A. (1999). Service Co-ordination: Professionals' View on the Role of a Multi-agency Service Co-ordinator for Children with Disabilities. The Handsel Trust, Birmingham.

[2] Cass, H., Price, K., Reilly, S., Wisbeach, A. & Mcconachie, H. (1999). Supporting children with multiple disabilities. Child: Care, Health and Development 25(3), 191–211.

[3] Parkes J., Donnelly, M., Dolk, H. & Hill, N. (2002). Use of physiotherapy and alternatives by children with cerebral palsy: a population study. *Child: Care, Health & Development,* 28(6), 469–477.

[4] Watson, D., Townsley, R., & Abbott, D. (2002). Exploring multi-agency working in services to disabled children with complex healthcare needs and their families. *Journal of Clinical Nursing*, 11(3), 367–375.

[5] Choi, B. C. K., & Pak, A. W. P. (2006). Multidisciplinarity, interdisciplinarity and transdisciplinarity in health research, services, education and policy: 1. Definitions, objectives, and evidence of effectiveness. *Clinical and investigative medicine. Médecinecliniqueetexperimentale*, 29(6), 351–364.

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meeting together to discuss their findings and establish goals. For instance, a health visitor, special needs teacher and social worker might work together to develop a package of care for a tube-fed child who is about to attend school. Assessment and care planning are completed at different agencies but with a multi-agency discussion

- Trans-disciplinary working is described as a more holistic approach that shifts the focus of the service delivery to both the child and family. The initial assessment examines the needs and wishes of the family and child so that the package of support and care is designed specifically to meet their needs. The "primary provider" in this approach is responsibility for providing, advising on and co-ordinating services for the child and family[1].

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**Figure 1. Main features of multi-disciplinary, inter-disciplinary and trans-disciplinary working[2]**

| Features | Multi-disciplinary (separate services) | Interdisciplinary (co-ordination of services) | Transdisciplinary (synthesis of services) |
|---|---|---|---|
| Likely perceptions of service quality by families | Low | Medium | High |
| Focus of service delivery | Single agency e.g. healthcare | Multi-agency e.g. health & social care | Family and child, e.g. the needs & wishes of the family & child |
| Professional roles & knowledge | Single discipline | Single discipline | Multi-discipline |
| Assessment & provision | Separate professionals/ agencies | Separate agencies but with multi-agency discussion | Multi-agency, in partnership with family & child |
| Partnership with family and child | Low | Medium | High |
| Criteria for measuring quality of provision | Goals set by single agencies/professionals | Goals set by multi-agency team with input from families | Goals set by family and child with input from professionals |
| Funding | Single agency | Single or multi-agency | Multi-agency |
| Who co-ordinates services | Family | Multi-agency group | One key professional |

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While definitions vary, the common take-away message is that for children with multiple needs and their families, more elaborated team approaches facilitate more holistic care planning and better coordinated delivery. They also benefit providers who have more immediate access to a wider range of expertise and collegial support when addressing complex problems.

For example:
- Researchers investigated views from professionals about multi-agency working and found that they were "overwhelmingly positive"[3]. Participants indicated that improvements to their working lives (e.g., professional development, communication,

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[1] Watson, D., Townsley, R., & Abbott, D. (2002). Exploring multi-agency working in services to disabled children with complex healthcare needs and their families. *Journal of Clinical Nursing*, 11(3), 367–375.

[2] Watson, D., Townsley, R., & Abbott, D. (2002). (See n.1 above).

[3] Abbott, D., Townsley, R., & Watson, D. (2005). Multi-agency working in services for disabled children: what impact does it have on professionals? *Health & social care in the community*, 13(2), 155–163.

collaboration, and relationships with families) promoted more effective care to support and meet family needs

- Evaluation of the *Rural Beginnings Project* which uses a trans-disciplinary approach to build the "team around the child"[1] observed increased parent capacity and uptake of interventions by parents because of the common understanding and reinforcement of strategies; high levels of satisfaction with communication with staff; high levels of staff commitment fostering a strong collaborative organizational culture.

What also emerges is a strong sense that more elaborated team approaches support and empower family caregivers.  Where joint working among formal providers is limited, informal caregivers may take on more of the coordinating role and the burden which that entails; where joint working among formal providers is more extensive, and professionals do the coordinating, caregiver burden is lessened.  Further, where coordination across multiple providers is led by "one key professional," supported by a team, the focus of service delivery can shift more completely from what individual agencies can do, to what children and families need.

### 3.1.2 Key Workers

The "Key Worker" role is thus frequently associated with joint working.  For example, in their examination of a multidisciplinary team at the Ronnie MacKeith Child Development Centre, Derbyshire Children's Hospital (UK), the researchers found that a Key Worker is "essential" to manage appointments and ensure effective communication between the child, parents, and various providers like pediatrician, physical therapist, occupational therapist, speech and language therapist, clinical psychologist, social worker, and representatives of education services[2].

Key Workers also provide information, support and facilitate coordination of health, educational and social services.  An evaluation of a program for families with visually impaired children found that Key Workers provided crucial information, support and liaison[3].

Other studies have observed that:

- The Key Worker role can be seen as a best practice in the care of children with complex needs, since "parents are given choice, throughout the child's life-journey, to have a

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[1] Alston, M., Barber, N., Mlcek, S., & Witney-Soanes, K. (2007). Draft Interim Invest to Grown Evaluation Report. Wagga Wagga: Charles Sturt University.

[2] Morton, R., Billings, K., Hankinson, J., Hart, D., Nicholson, J., Rowlands, A., Saunders, R., &Walter, A. (2003). Individual responsibilities in multidisciplinary working. *Current Paediatrics*, 13(1), 23–29.

[3] Rahi, J. S., Manaras, I., Tuomainen, H., & Hundt, G. L. (2004). Meeting the needs of parents around the time of diagnosis of disability among their children: evaluation of a novel program for information, support, and liaison by key workers. *Pediatrics*, 114(4), e477–482.

person who could act as a coordinator of care and who has in-depth knowledge of them and their child"[1]

- Peer support is an important complement to Key Worker services because it provides "valued opportunities to meet and share information and support".  In addition, having a diverse team of professionals was "an asset in providing a range of expertise"[2].

In other words, while valuable in and of itself, the value of the Key Worker role can be magnified when they lead, or are embedded within, collaborative teams or other forms of "joint working."

### 3.1.3 Children's Treatment Network (CTN) of Simcoe York

In the *Formative Evaluation*, Key Informants identified the Children's Treatment Network (CTN) of Simcoe York as an exemplary local model of care for children with ongoing complex needs and their caregivers.

Established in 2005, CTN is funded by the Ministry of Children and Youth Services.  It takes a broad-based team approach to care.  According to its website, CTN "is a partnership of agencies and organizations committed to providing comprehensive care and coordinated services to children and youth with multiple special needs who live in Simcoe Country and York Region." CTN now has over 50 partners including schools, hospitals, rehabilitation providers, recreationists, social and community services "who serve kids with special needs."

In 2008 CTN received the Rotman Award in Pediatric Home Care Innovation from the SickKids Foundation; in 2009, it received a Public Sector Leadership Award from the Institute of Public Administration of Canada (IPAC) and Deloitte.

CTN has been extensively documented and evaluated.  Details of the CTN's organization and operation can be found at http://www.ctn-simcoeyork.ca/aboutctn/questionsandanswers.php

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[1] Carter, B., Cummings, J., & Cooper, L. (2007). An exploration of best practice in multi-agency working and the experiences of families of children with complex health needs. What works well and what needs to be done to improve practice for the future? *Journal of clinical nursing*, 16(3), 527–539.
[2] Greco, V., Sloper, P., Webb, R. & Beecham, J. (2006). Key worker services for disabled children: the views of staff, Health and Social Care in the Community, 14 (6), 445-52.

and in a number of published articles[1,2,3,4].  A listing of selected evaluation tools used by the CTN can be found in Appendix A.

A number of characteristics seem particularly relevant to the CF:
- First, CTN uses a common assessment, shared client record, and single plan of care which establish the operational nexus for inter-professional and inter-organizational team focused on the needs of the child and family.  A designated care coordinator (similar to a Key Worker) is the link between the family and the provider team

- Second, care plans are built around the family's vision and goals – "where do families want to be in six months or a year?"  Goals vary extensively but are often as simple as "my child wants to go to a birthday party," or "my child wants to walk/talk."  The job of the team is to put in needed services and supports to achieve these goals

- Third, joint working is encouraged through mechanisms including:
  - Financial incentives: participating organizations receive funding
  - Accountability:  contracts signed by all participating organizations identify expectations including participation on care teams, information sharing, and compliance with privacy and confidentiality requirements which have been determined in collaboration with health regulatory colleges
  - Technology: virtual team meetings are technology-enabled; an electronic care record is accessible to all team members and families
  - Regular meetings and training sessions: monthly Network meetings discuss organizational challenges and opportunities; monthly clinical meetings raise issues and work toward solutions

- Fourth, CTN undergoes regular evaluation at individual and Network levels:
  - Care plans are evaluated to ensure that all necessary services have been put in place and that goals have been met

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[1] Thurston, S., Paul., L., Ye, C., Loney, P., Browne, D., Browne, G., Wong, M., Thabane, L., & Rosenbaum, P. (2010). Clinical study. System integration and its influence on the quality of life of children with complex needs. *International Journal of Pediatrics*. Vol 2010. 1-12. http://www.hindawi.com/journals/ijped/2010/570209/cta/

[2] Thurston, S., Paul, L., Loney, P., Wong, M., & Browne, G. (2010). Clinical study. The quality of life of a multidiagnosis group of special needs children: Associations and Costs. *International Journal of Pediatrics*. Vol 2010. 1-13. http://www.hindawi.com/journals/ijped/2010/940101/cta/

[3] Thurston, S., Paul, L., Ye, C., Loney, P., Browne, G., Thabane, L., & Rosenbaum, P. (2010). Interactions among ecological factors that explain the psychosocial quality of life of children with complex needs. *International Journal of Pediatrics*. Vol2010 . 1-10 http://www.hindawi.com/journals/ijped/2010/404687/cta/

[4] Ye, C., Browne, G., Grdisa, V., Beyene, J., & Thabane, L. (2012). Measuring the degree of integration for an integrated service network. *International Journal of Integrated Care*. 12, 1-15. http://www.ijic.org/index.php/ijic/article/viewArticle/835/1783

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- o Validated instruments such as MPOC (Measure of Processes of Care) and the CANS Tool (Child and Adolescent Needs and Strengths) are used to determine the extent to which parents' perceive that the services they receive are family-centred; additional instruments also measure health and social service utilization[1]

- Fifth, CTN has demonstrated a range of positive outcomes[2] including:
  - o For families
    - 91% family satisfaction
    - 89% of families who felt their most important issues were addressed
    - 77% who reported improved communication with providers and quality of services
    - 58% who reported their child's participation at school improved
    - 50% experienced increased hope and ability to cope
    - Stronger networks of families who share experiences and knowledge with other families to help them meet the day-to-day challenges
  - o For providers and system
    - Development of a strong network of partners spanning health, education, and community sectors.

### 3.2 Follow-Up Key Informant Interviews with CF Staff and Key Workers

We asked CF staff and Key Workers about progress during the project's third phase; they highly rated its performance.  They noted that:

- **Building on the success of earlier phases, the CFP3 had seen a positive shift toward longer-term goal-setting.**  Staff and Key Workers reported that, in contrast to the CF's earlier phases, where the focus had often been on accessing funds to deal with immediate problems, Phase 3 had seen a stronger emphasis on forward planning.  This emphasis facilitated useful dialogue between caregivers and Key Workers about what was needed to sustain the caregiver, as well as the CMC and family.  It had promoted creative thinking about how resources could be used to meet caregiver needs through recreation, education and skills development.  It has also given Key Workers new opportunities to engage caregivers, build trust, and get at underlying problems with the aim of building more lasting solutions

- **The new administrative review process had reinforced this success.**  In the CF's initial phases, conversations between Key Workers and caregivers often focused on funding,

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[1] Browne, G., Arpin, K., Corey, P., Fitch, M., and Gafni, A. (1990). Individual correlates of health service utilization and the cost of poor adjustment to chronic illness. Medical Care 28(1), 43–58.
[2] Children Treatment Network (CTN) of Simcoe York. (2013). Annual Report 2012-2013. Accessed on-line at: http://www.ctn-simcoeyork.ca/resources/2012-2013%20CTN%20Annual%20Report%20Online.pdf

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since Key Workers decided how the dollar amounts would be allocated. However, funding decisions during CFP3 were made by an administrative team after it reviewed the goals set by the Key Worker and caregiver; as a result, Key Worker/caregiver conversations focused more on goals. Key informants uniformly supported this change which they said achieved greater consistency in decision-making. Moreover, by shifting sometimes contentious funding decisions to the administrative level, it had improved relationships between Key Workers and families who could now focus more on problem-solving and longer-term planning.

Some challenges remained:

- **Not all caregivers embraced goal-setting.** As a group, caregivers who had participated in earlier phases of the CF were more difficult to engage in goal-setting; they seemed to have fixed ideas about the CF, about the amount of money they would receive (based on what they had previously received), and how it should be spent. In some cases, caregivers presented receipts for purchases even before the goal-setting process had begun

- **Caregivers from the earlier phases of the CF were less inclined to focus on their own needs;** these caregivers had been used to dealing with the immediate problems experienced by their child and experienced a difficult time moving beyond that

- **Some caregivers found the assessment and goal-setting process taxing.** Key Workers expressed that the length of the CF assessment and goal-setting process – often lasting two hours, but sometimes lasting up to six hours – was quite demanding for some families. As a result, the assessment and goal-setting process often required multiple visits

- **CF staff and Key Workers faced time constraints.** CF staff and Key Workers noted there hadn't been sufficient time in Phase 3 to complete the assessments and engage in goal-setting, establish linkages with other providers, and follow-up to truly understand how everything was working for families. They stated that the entire process would be smoother and likely more successful if they had a longer time frame to work with.

Key informants offered a number of suggestions for improving CF's performance:

- **Provide Key Workers with ongoing training.** Key Workers and CF staff identified that additional and ongoing training around problem-solving and goal-setting would enhance their abilities, ensure greater consistency in approaches, and improve the CF's performance

- **Clarify administrative guidelines around money.** Key Workers said that clearer guidelines around what money families are eligible for and what they are likely to

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receive would allow them to concentrate more on setting and attaining goals.  Once funding decisions were identified, it would be beneficial for the Key Workers to be informed of the decisions as often the caregivers contact them with related questions

- **Shorten the front-end assessment.**  Currently, assessments collect medical information about the child which is also collected elsewhere; duplication could be reduced by using a common electronic record

- **Purposefully design the process so that it takes place over two to three visits**.  Caregivers and Key Workers suggested that it would be beneficial to extend the goal-setting process over multiple visits to develop a fuller picture of what the family needs, and how changing needs might best be met

- **Consider that not all care plans may require dollars.**  While all caregivers benefitted from additional funding, Key Workers felt that families with lower incomes who could not afford to purchase needed services on their own, benefitted the most; the funding component of the CF could be more closely tied to economic means

- **Better integrate the CF within the ICCM and with other providers.**  CF staff and key Workers reported that the CF had positively impacted on working relationships between Sick Kids, the TC CCAC and Holland Bloorview; this success could be strengthened by bringing together other organizations and providers who are also caring for the same children and families.  Not having a record of how other providers were involved with CF clients meant guessing about how best to use the CF's resources, whether care plans were aligned, and how much follow-up was needed.

## 3.3 Analysis of Caregiver Assessment and Care Plan Data

A total of 42 assessments were completed during the third phase of the CF; these included longer-term goals and plans to achieve them.

### 3.3.1 Goal Identification

A range of goals, co-created by caregivers and Key Workers, are recorded in the assessments.  Broadly speaking, while some of these goals remained centred on the immediate needs of the CMC, most look to the longer-term needs of the caregiver and the importance of maintaining social relationships within and beyond the family.  All speak to the importance of being able to "step back" to look toward the horizon.

According to one assessment:
- "[Mother] was able to clearly articulate the care needs of her family, and how the changing needs and dynamics have allowed her to approach the situations from a fresh perspective where she can acknowledge the self-care that she needs to focus on.  [Mother] feels that approaching things and taking small steps has allowed her to connect with resources that she was hesitant to use previously."

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**Some goals still focused on the (mostly medical) needs of the CMC**.  For example:

- Incontinence supplies emerged as a significant issue for some families: "Mother's largest concern is the financial burden of the diapers and the wipes"

- Other caregivers expressed concern about the pain experienced by their child; one wanted to "purchase more private physical therapy to optimize gross motor function and decrease pain"

- A number of caregivers identified medication costs as a "significant source of financial stress".  One assessment states that:  "Mother would like to be able to focus on securing funding to assist with the coverage of medication, over the counter medication and other supplies used for the client's daily activities of living"

- Other goals look toward additional and or alternative therapy to promote the wellbeing and development of the child (e.g., horseback riding and pool therapy sessions).

**Many goals were caregiver-focused.**  Key Workers said that they encouraged caregivers to sort through their own physical, social and mental needs and to consider what was required to maintain their resilience and capacity; this focus comes through in many of the goals identified in assessments.  For example:

- One caregiver wanted to develop computer skills to be able to seek out information and apply for supports online

- Other caregivers wanted to take steps to improve their job skills so that they could re-engage in paid work outside the household:  For example, "Mother would like to be able to return to work part-time so that she can discontinue support of Ontario Works" [the provincial income support program]

- Another caregiver expressed her desire to engage in creative activities:  "Mother is willing to explore future next steps on how to support [her] dreams, such as, creative writing, resume writing..."

- Many caregivers aimed for more alone time and more time spent in community/social activities.  For example, one caregiver wanted to have time for "Attending support meetings in the community.  Recognizes the importance of these outlets and will focus on enhancing this aspect of [their] life"

- Mental health was also an issue.  As outlined by one goal identification, the caregiver wished to "Explore options in the community to support her mental health (counselling options) to develop and ensure an established therapeutic relationship to support her emotionally."

**Other goals looked more broadly toward maintaining the integrity of the family.** Caregivers, Key Workers and CF staff repeatedly commented on the high levels of stress experienced by many families caring for CMC; family breakup was a too-frequent outcome. Not surprisingly, many of the goals recorded in the assessments aimed at sustaining families. For example:

- Some caregivers felt that relationship building activities would help maintain their own resiliency. "Mother noted that it is important for her and her husband to spend some quality time together alone." The Key Worker was able to connect this family to community resources to provide the parents with respite and allow them the time to reconnect and strengthen their marriage

- Other caregivers identified the importance of building up familial relations: "Mother would like to continue to have family time together as it has really improved their relationship with their daughter and between her and her father in the past year"

- Some caregivers identified a strong desire to be able to give more attention to other family members: "Mother further discussed her desire to have her children enrolled in more physical activities… The benefits of this involvement would be twofold; the children would be exposed to these activities, and subsequently mother would not have to entertain or supervise the children at home if they are involved in more extra-curricular activities (i.e. march break, summer camps, sports etc.). Mother also highlighted 'family time' as another thing that is important to her and to the siblings."

### 3.3.2 Care Plans

Care plans developed to achieve these goals reveal a similarly broad range, and considerable imagination. Table 1 provides examples of typical care plan elements and the frequency with which they appear.

Table 1: Care Plan Summary

| Types | Examples | Number of Clients |
|---|---|---|
| **CMC Supports** | | |
| Health Care Services and Supplies | • New mattress <br> • Medications <br> • Incontinence supplies <br> • Protein supplements <br> • Increased physical therapy <br> • Increased occupational therapy <br> • Look into pet therapy | 23 |
| **Caregiver Supports** | | |
| Self-Care | • Gym membership <br> • Counseling services <br> • Yoga | 10 |
| In-home Support/ Respite | • In home respite <br> • Support during the night <br> • Assistance with household chores | 10 |

| | | |
|---|---|---|
| Connections to Community Supports | • Explore community agencies that might be available for emergency respite<br>• Connect with church services<br>• Plan Toronto | 9 |
| Health Care Services | • Booking physician and dentist appointments<br>• Acupuncture | 8 |
| Home Modifications/ Equipment | • Ceiling lifts<br>• Apply to Habitat for Humanity to determine eligibility for an accessible home<br>• Generator | 8 |
| Transportation | • Obtaining a modified vehicle<br>• Applying for funding for vehicle modifications<br>• Purchasing Metropass (public transit pass) | 3 |
| Employment Supports | • Exploring next steps to improve resume and engage in volunteering to identify potential careers | 2 |
| **Family Supports** | | |
| Relationship Building | • Go out for dinner with the family<br>• Family skiing<br>• Explore funds for family outings<br>• Counseling<br>• Parent alone time<br>• Sponsorship of father | 13 |
| Activities Socializing/ Hobby | • Involve siblings in sports<br>• Camp | 7 |
| Personal Items | • Winter clothes<br>• Furniture | 7 |
| Connect to Financial Supports | • Ensuring all charities are being looked into (president's choice, Jump Start etc)<br>• Applications for Christmas Toy/Basket through Salvation Army<br>• Reach out to additional possible funding sources i.e. disability tax credit | 6 |
| Skills Development | • Tutoring support for sibling<br>• Link siblings to Young Carers program<br>• Beverly School to learn techniques | 2 |

As the numbers show, the health care needs of CMC still figure prominently in care plans:

- About half (23 of 42) of these plans include medical supplies (ranging from a special mattress to medications, incontinence supplies and protein supplements) and health care (e.g., physical therapy, occupational therapy and even pet therapy) for the child.

The list of supports for caregivers is longer and more diverse, stretching well beyond health care. Plans encompass (in order of descending frequency):

- Self-care (including gym memberships, counseling and yoga)
- In-home supports and respite (including coverage at night and assistance with household chores)
- Connections to community supports (including respite agencies, church resources, and organizations like Plan Toronto which provide specialized services for families)
- Health care (including physician, dentist and acupuncture services)
- Home modifications and equipment (such as ceiling lifts, a back-up generator, and accessible housing)

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- Transportation (such as obtaining a modified vehicle, applying for funding for vehicle modifications, and purchasing a Metropass)
- Employment supports (including support for improving a caregiver's resume and engaging in volunteer work to identify potential careers).

Services and supports for the family as a whole are similarly diverse; they encompass:
- Relationship building  (e.g., go out for a family dinner, skiing, family outings, family counseling, parent alone time)
- Socializing (e.g., sports, summer camp for siblings)
- Personal items (including  winter clothes for the family or furniture for the home)
- Connections to financials supports (such as charities, Christmas toy baskets, tax credits)
- Skills development (including tutoring for siblings, links to Young Carers program).

## 3.4 Caregiver Interviews

Our interviews with caregivers revealed high levels of satisfaction with, and support for the CF. The caregivers interviewed had nothing but praise for this CF which they described as "amazing", "wonderful", "fantastic" and "positive".

One caregiver, who said that caregiving can be overwhelming, described the CF as "hands reaching out."  Another said that the CF had met the needs of caregivers and "well beyond."

**The CF's financial support was vital**.  Caregivers emphasized that the CF provided needed care, respite and a sense of peace; the funding helped to relieve stress from financial concerns.  For example, funding had been used to purchase medications and supplies (e.g., drainage bags, hygiene products) for the child.  Further, the whole family had enjoyed benefits since the financial support allowed caregivers respite to focus on other family members improving their mood, self-esteem and overall well-being.  One caregiver had used the funding to reconnect with extended family living outside of Canada; another had purchased a camera for monitoring so that they could devote time to other family members without worrying so much.

**The personal connections developed with Key Workers were very valuable**.  Caregivers said that the best aspect of the CF was the connection with the Key Worker.  Key Workers went above and beyond to understand and support caregivers.  Key Workers were described as extremely understanding and active listeners.  By connecting to Key Workers, caregivers felt that they were important, more connected, and more knowledgeable about services and providers in their community.  The Key Worker had become the essential "go-to" person for ongoing advice and support.

As a result of the CF:
- **Caregivers said they were more able to continue to care.**  In the short-term, the CF offers "peace of mind", emotional support and much needed respite to recharge and refresh caregivers.  In the long-term, it helps to improve their confidence and resilience

- **Caregivers had new opportunities to connect with other families.** The CF helped caregivers to build a network of mutual-support and knowledge transfer (e.g., sharing information about doctors, specialists and medications). While not all caregivers had actually connected with other families, those who did said they had become closer to other families and that they supported each other

- **Caregivers were better able to connect with needed formal services.** As one caregiver shared, it "open[ed] her eyes" to the different services available and feeling more connected. By speaking with a Key Worker who is knowledgeable about what services are available, caregivers felt more confident. Information and "out-of-the-box" thinking helped to "weed out some of the [alternatives]" saving time, money and reducing stress.

Caregivers made the following suggestions:

- **Conduct assessments more frequently.** Because CMC are often medically unstable and their needs can change rapidly, more frequent assessments (e.g., semi-annually or every 9 months) can ensure more appropriate and effective care for CMC and families

- **Use different funding methods.** One caregiver suggested that funds be provided in the form of a credit or gift card to make management and tracking easier; for example, a gift card for Shoppers Drug Mart could be used for medications and other medical supplies.

### 3.4.1 Additional Caregiver Feedback

A number of caregivers (aside from those we interviewed), provided feedback via their Key Workers. This feedback was consistently positive and highlighted key observations made earlier.

Key Workers passed on the following comments:

- "Mother described that they are a "different family." It was an "amazing" support. Mom and Dad went on "dates." It changed the spousal relationship; they are in a much better place

- Mother will obtain a gym membership. Mother will also purchase cleaning supports. Described feeling like she was given a "fairy godmother"

- Mother felt that supports were actually being put in place. She also felt there was closer oversight into the family. It gave them more connections with help. They were very happy that it was presented to them, which is not typical of support programs."

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## 4.0 Conclusions

CMC and their caregivers face formidable challenges.  In addition to accessing and managing a range of medical and non-medical services and supports required to maintain the health and wellbeing of the child, caregivers often struggle to maintain the integrity of their families, to remain connected to their broader social networks, and to engage, where possible, in paid employment; the personal costs can be considerable.

While caregiver burden and stress are often conceptualized primarily or solely as a function of the needs of the CMC, the results of this evaluation clarify that caregiver burden and stress also result from the sheer effort needed to navigate "non-systems" of unconnected services and providers, each with varying eligibility requirements, assessments, benefits and out-of-pocket costs.  Our earlier *Formative Evaluation* revealed that CMC averaged 7 medical conditions, and required care from up to 14 medical specialists, in addition to numerous non-medical supports spanning home care, community services, housing and education.

This is where the CF generates so much value.  All stakeholders agree that by having specially trained Key Workers engage "at risk" caregivers to identify problems, create solutions, and connect with needed services and supports across different providers and sectors, the caregiver role is validated and reinforced, the family unit is strengthened, and CMC are more likely to get the supports they need to continue to live at home with less likelihood of "default" to hospital and residential care.

The direct costs of the CF are relatively modest; Key Workers access budgets averaging about $3500.00 per caregiver per year to co-create support packages that validate and reinforce the caregiver role.  The dividends are substantial: in addition to responding to immediate needs and managing crisis, caregivers are able to look ahead, establish long-term goals, and plan for the future.  As a result, caregivers are more able to think about what they need, and more confident about their ability to continue to care for their families.

Our previous *Formative Evaluation* demonstrated strong support for the continuation and expansion of the CF; the current evaluation aimed to provide insight into "how" the CF can continue to evolve to maximize value for CMC, caregivers, and other stakeholders.  In summary, we observed that:

- **CF staff, Key Workers and caregivers continued to be strong supporters and advocates for the CF.**  CF staff and Key Workers highly rated the performance of the CFP3; caregivers described the CF generally and Key Workers specifically as "amazing" and "wonderful"

- **Caregivers valued the financial assistance provided by the CF.**  Caregivers said that the money goes a long way to addressing immediate care needs (such as incontinence supplies, medications and therapy), thus giving caregivers respite and relief from

financial concerns. It also allows caregivers to begin to think about what they need to stay healthy and resilient over the longer term (e.g., skills enhancement, counselling, creative activities)

- **All stakeholders applauded the CF's shift toward goal setting.** One caregiver recalled how the process had "open[ed] her eyes" to the different services available. CF staff and Key Workers said this shift catalyzed more meaningful dialogues between caregivers and Key Workers; it presented new opportunities for Key Workers to actively engage with caregivers, establish trust and develop personal relationships. Further gains could be achieved by "spreading" the goal-setting process over 2 or 3 visits, thus developing a more complete picture of family needs and how they change over time

- **In setting future goals, more light was shed on caregiver needs.** Key Workers used goal setting as an opportunity to encourage caregivers to sort through their own physical, social and mental needs and to consider what was required to maintain their resilience and capacity; such goals also frequently spoke to the integrity of the family as caregivers considered ways to strengthen relationships with siblings and partners

- **The administrative review process, which shifted budget allocations away from Key Workers, strengthened the goal-setting process.** Not surprisingly, in previous phases of the CF, when Key Workers had made budget decisions themselves, their conversations with caregivers had often focused on dollars; as budget decisions moved to the administrative team, which made budget decisions based on goals and care plans, conversations had broadened to consider what was needed to sustain the CMC and caregivers. According to Key Workers, in addition to leading to greater consistency, this often improved relationships with caregivers, and allowed for more thinking about the future

- **There are opportunities to further improve the CF's performance.** Key Workers noted that although they were able to connect CMC and caregivers with other needed services and providers, they did not always know what others actually did for their clients, or what follow-up was needed; moreover, different providers often required their own assessments, leading to unnecessary duplication and time spent by families giving the same information. They suggested that the CF be more closely integrated with the Integrated Complex Care Model (ICCM) through mechanisms including a common care record, and with other providers through team approaches; this is consistent with a growing international literature which concludes that more elaborated team approaches and joint working facilitate more holistic care planning and better coordinated care delivery for children with multiple chronic needs.

## 5.0 Recommendations

Based on the evaluation findings, we offer three sets of recommendations to guide the ongoing development of the CF, emphasizing, once again, that it continues to draw strong support from all stakeholders.

### 5.1 Continue to Strengthen the CF

Our first set of recommendations aims to improve the performance of the CF without requiring any major changes to its current structure or direction.

**5.1.1 Provide planned opportunities for learning.** CF staff and Key Workers suggested, and we recommend, that CF personnel engage in regular training and professional development opportunities particularly around the goal-setting process. In addition to encouraging more consistent approaches, regular learning opportunities could be used to review the performance of the CF on an ongoing basis, surface emerging challenges, make mid-course corrections as needed, and consolidate best practices. Peer 'coaching,' where CF veterans are teamed with newer members could assist with knowledge transfer within the CF and ensure the reproduction of an "institutional memory" even as personnel change.

**5.1.2 Consider "spreading out" the goal-setting process**. Key Workers reported that conducting assessments and setting goals in a single session had sometimes proved taxing for caregivers; they also felt that more frequent caregiver/Key Worker interactions could strengthen relationships and flag changing needs as they arose. Key Workers suggested, and we recommend, that the goal-setting process be spread over two or three visits during the course of each year.

**5.1.3 Augment the administrative review process.** Shifting responsibility for budget allocations to an administrative working group had allowed Key Workers to concentrate more on goal setting; this should continue. Further gains could be realized by clarifying the administrative criteria used to make decisions about how much caregivers are eligible for and how much they actually receive. In addition to improving transparency, this would relieve Key Workers of the need to try to explain to caregivers, not always satisfactorily, how decisions had been made.

**5.1.4 Aim to assess outcomes.** In this evaluation and in the previous *Formative Evaluation*, we have documented overwhelming support for the CF from all stakeholders as well as many first-hand accounts of success; however, we have not yet been able to demonstrate hard outcomes such as improved wellbeing for informal caregivers and CMC, or more cost-effective use of formal care resources. Such evaluation, prized by decision-makers, will likely require the use of a control group (CMC and caregivers with similar levels of need who do not receive the CF as compared to those who do) and an extended time frame (stretching 5 to 10 years into the future). Even if not immediately doable, planning for such evaluation can begin now. A good first step would be to elaborate and pilot a set of qualitative and quantitative outcome measures, possibly linked to the ongoing development of the ICCM scorecard.

## 5.2 Encourage Collaboration and Joint Working

Our second set of recommendations aims to import mechanisms, separately or in combination, which promote collaboration and "joint working" within and beyond the CF.

### 5.2.1 Position Key Workers to work with teams.
As competent and dedicated as Key Workers clearly are, individuals cannot reasonably be expected to have the time and the scope of knowledge to cover the sheer range of services and supports required by children with multiple chronic needs and their caregivers, especially when those needs go well beyond conventional health care. Accordingly, the literature often associates the Key Worker role with cross-disciplinary, cross-organization teams; such teams, including caregivers as active participants, are at the heart of the Children's Treatment Network of Simcoe York (CTN). Key Workers suggested, and we recommend, that stronger linkages be forged between the CF and other programs and providers also serving CMC and caregivers such as the ICCM, other home and community care providers, rehabilitation, mental health, primary care, and school boards; such linkages can be operationalized through consultative teams whose membership and focus would adjust to the changing needs of the CMC and caregiver (e.g., from medical care to rehabilitation as appropriate).

### 5.2.2 Establish electronic care plans accessible to providers and caregivers.
Key Workers suggested that electronic records shared with other programs and providers involved in the care of their clients could improve the continuity and coordination of care and promote better follow-up; making these records accessible to families would empower them to become more active partners in care. Our quick review of the international literature suggests that electronic care plans are increasingly seen as a best practice; our review of the CTN suggests not only that the technology is available but that valid issues around information sharing and confidentiality can be resolved in partnership with regulatory agencies. Additional expertise and insight may be accessed through eCHIN (the Electronic Child Health Network), which is also supported by SickKids, and which hosts a province-wide integrated electronic health record for children.

### 5.2.3 Introduce technology-enabled virtual rounds with caregiver participation.
Technological advances mean that teams no longer have to meet at a single location with the travel and scheduling challenges that can pose; they can meet virtually via widely used and easily accessed electronic platforms such as OTN (Ontario Telemedicine Network). Virtual rounds, where actual or simulated cases are considered, can bring teams together to think about how best to meet the needs of CMC and caregivers; they can also be used to inform stakeholders about emergent issues, cutting edge innovations and best practices. We recommend that virtual rounds be initiated not only to facilitate joint working among providers, but to promote greater participation of caregivers and families in decision-making.

### 5.3 Build Toward a Network

Our third set of recommendations looks to the future evolution of the CF as the nucleus for an integrating network focused on the caregiver and CMC as a single "unit of care." These recommendations may not be immediately attainable; nevertheless, in the same spirit of longer-term goal-setting for caregivers, we see them as contributing to longer-term goal-setting for the CF.

**5.3.1 Use financial incentives.** The literature underscores the fact that mechanisms of joint working and care integration offer a range of benefits to CMC and families requiring multiple medical and non-medical services and supports over extended time periods; however, it also notes that such mechanisms are rarely "free." At the very least, participants will incur transaction costs related to the need to communicate and coordinate with others, and to make adjustments to practice. One approach is to offer financial incentives; for example, CTN offers funding to network members in return for their voluntary agreement to share information, participate in teams, and contribute to a single plan of care. We recommend that the CF consider using some of its budget resources to bring more partners to the table; we further recommend that the TC LHIN consider enhancing the CF budget to enable it to act as the nucleus for a provider network.

**5.3.2 Establish accountability agreements.** While economic incentives may bring new partners to the table, formal accountability agreements can clarify expectations and set performance targets once they are there. Accountability agreements can also clarify what families can expect and what is expected of them. Even prior to establishing a formal network, the CF can elaborate accountability agreements with its current partners.

**5.3.3 Engage in regular partner meetings.** During its third phase, the CF instituted, with considerable success, an administrative working group to review care plans and allocate resources. We think that the mandate and membership of this working group could be expanded to establish the foundation for an emerging network. A key activity of this group would be to convene, at regular intervals, meetings of current or possible partners with the aim of developing a more complete picture of how different organizations can work together to meet the needs of CMC, caregivers and families.

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## Appendix A: Selected Assessment Tools Used for the CTN Child & Family Interview

The Child and Family Interview is composes of several measures.  The interview is conducted by researchers out of McMaster University and the interviewee is the consenting parent/guardian most knowledgeable (PMK).  The parent returned a signed consent form to McMaster University indicating their willingness to participate.  The telephone interviews lasted about 1 hour.

**Caregiver Burden**
The Impact on Family (IOF) scale determines the effects of a chronic illness on parents and families.  Statements cover four dimensions: financial burden, family/social impact, personal strain and mastery.  More information about the scale can be found at:
http://www.apa.org/pi/about/publications/caregivers/practice-settings/assessment/tools/family-impact.aspx

**Child Behaviour**
Behaviour is measured using the Canadian National Longitudinal Survey of Children and Youth questionnaire (NLSCY) for children ages 2-19.  The questionnaire asks about how the child seems to feel or act regarding age specific behaviours such as getting into fights, inability to sit still and worrying.  More information about the questionnaire can be found at:
http://www23.statcan.gc.ca/imdb-bmdi/instrument/4450_Q2_V7-eng.pdf#page=161&zoom=auto,0,792

**Child Quality of Life**
The Pediatric Quality of Life Inventory™ (PedsQL™) is a generic measurement system developed by Varni et al. for use in children ages 2-18.  The shortened version consists of 15-items comprising three core scales and addresses the physical, emotional, social and school functioning.  More information about the tool can be found at: http://www.pedsql.org/

**Family Functioning**
Thirteen items taken from NLSCY population survey based on a subscale of the McMaster Family Assessment Device.  The items gather information on family functioning like: problem solving, communication, roles, affective responsiveness, affective involvement, and behaviour control.  More information can be found at: http://www23.statcan.gc.ca/imdb-bmdi/instrument/4450_Q2_V7-eng.pdf#page=61&zoom=auto,0,792

**Health of PMK**
The Kessler Psychological Distress Scale measures PMK symptoms of depression and anxiety, a frequent accompaniment of depression.  Ten questions measure the frequency of feeling: sad, nervous, restless, hopeless, worthless, everything was an effort, tired for no good reason, so

nervous things won't calm down ect.  More information about the survey can be found at: http://www.nevdgp.org.au/files/programsupport/mentalhealth/K10_English%5B1%5D.pdf

**Parenting Practices**

NLSCY parenting scale was used and consists of twenty-five questions adapted from the Parent Practices Scale.  The scale measures positive interaction, hostility, consistency, punitive.  More information about the scale can be found at: http://www23.statcan.gc.ca/imdb-bmdi/instrument/4450_Q2_V7-eng.pdf#page=192&zoom=auto,0,792

**Parents' Perception of Family-Centeredness of Services**

Measure of Processes of Care (MPOC) is a 20 item, well-validated, and reliable self-report measure of parents' perceptions of the extent to which the services they and their child receive are family-centered.  Seven-point scale to describe the extent to which they experience service provider behaviours across five domains (enabling and partnerships, providing general information, providing specific information, comprehensive and coordinated care, and respectful and supportive care).  More information about the measure can be found at: http://www.canchild.ca/en/measures/mpoc56_mpoc20.asp

**Social Support**

The level of social support of the PMK was assessed using an eight item shortened version of the Social Provisions Scale.  Different constructs were measured: guidance, reliable alliance, attachment.  More information can be found at: http://www23.statcan.gc.ca/imdb/p3Instr.pl?Function=assembleInstr&lang=en&Item_Id=119788#qb120290

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