“Many Hands; One Circle”

Designing a Child and Family Centred Continuing Care Model for Aboriginal Children with Complex Health Care Needs and their Families on Vancouver Island

February 10, 2011
“The health of Aboriginal children is a balance between the physical, spiritual, emotional and cognitive senses of self, and how these interrelate with family, community, world and the environment, in the past, present and future. The mainstream health system often takes a piecemeal approach to the health of Aboriginal children, defining them by their problems rather than in this broader context”.

Many Hands, One Dream, Principles for a New Perspective on the Health of First Nations, Inuit and Métis Children and Youth, Cindy Blackstock, Dawn Bruyere, Elizabeth Moreau, 2006

“Often within the fragmented system, the points of transitions are lost, where sectors, departments and agencies alike are not held accountable for the gaps in service and coordination...When health and home care systems are fragmented for children and youth problems include: multiple funding sources (health, education, social services and federal/provincial jurisdictions); multiple agencies involvement with different funding sources; inconsistent policies and the competition between organizations for funding and service provision contracts. These issues have lead to a system of care, which is fragmented, creates barriers for families to access services and is difficult for families to navigate.

Finding Our Way Back Home, Dr Brian Postl, Dean of Medicine at University of Manitoba And Chair of the Canadian Institute for Health Information (CIHI), 2006

“Children with complex health and social care needs have the same "ordinary" wishes and needs as other children. What matters most to them is being able to live at home, go to school, spend time with friends and participate in leisure and community activities with family and peers. This is also important to their families”.

Community Care UK Homepage, 2007

“It takes a village to get a child home... Successful discharge planning for children with complex respiratory needs is dependent on the collaborative efforts of all involved in the child’s care. ...This is achieved by facilitating the ‘village’ to develop the skills required to safely accept the child back into his community & provide the support needed by the family to maintain the care of the child at home. Inter-professional & family-centred collaboration across all sectors within the hospital and the child’s home community are central to our philosophy and key to our success. Community development through education/training & information sharing aimed at promoting consistency & continuity of care gives the child, family & community the confidence to make the transition home.”

Tracheostomy Care & Home Ventilation Program BC Children’s Hospital, Lisa Kwong RN, Debbie Cain RT, Hilda Perry PT, Fran Starr RN, Patricia Mendoza MD, 2009
"Many Hands; One Circle", February 10, 2011

First Nations On Vancouver Island

Source: First Peoples Language Map of British Columbia Project
## CONTENTS

A.) CONTEXT: THE TRANSITION FROM HOSPITAL TO HOME ........................................ 5

B.) PURPOSE OF THIS DOCUMENT ........................................................................ 6

C.) PURPOSE OF THE PROJECT ........................................................................... 8

D.) PROJECT SCOPE ............................................................................................. 8

E.) IDENTIFIED ISSUES FACING ABORIGINAL CHILDREN WITH COMPLEX CARE NEEDS AND THEIR FAMILIES ON VANCOUVER ISLAND ......................................................... 9

F.) VANCOUVER ISLAND ABORIGINAL CHILDREN DISCHARGED FROM BC CHILDREN’S HOSPITAL AND SUNNYHILL .............................................................. 10

G.) DOCUMENTING CURRENT AND FUTURE DISCHARGE PLANNING PROCESSES ........................................................................................................ 10

H.) IDENTIFYING KEY COMPONENTS OF PROMISING SERVICE CONTINUITY MODELS FOR CHILDREN WITH COMPLEX HEALTH CARE NEEDS .................................................. 12

I.) NEXT STEPS .................................................................................................... 16

APPENDICES ...................................................................................................... 17

APPENDIX I: SOME EXAMPLES OF PROMISING PRACTICES ................................. 18

APPENDIX II: VIHA RESIDENTS-BCCH & SUNNYHILL INPATIENT DISCHARGES, 2008/2009 ........................................................................................................... 29

APPENDIX III: KEY CONCEPTS AND DEFINITIONS .............................................. 30

APPENDIX IV: A MODEL BUILDING STRATEGY FRAMEWORK ............................... 35

REFERENCES ....................................................................................................... 37
Children with complex care needs generally depend on the provision of technical procedures to meet their daily care needs. With advances in medical science and technology, these procedures, once only undertaken in a hospital setting, can now be provided in the child's home and community. This means that many children with complex care needs can now live a more fulfilling and more normalized life. It also may mean an increased amount of stress and anxiety for parents who may be unprepared for the essential steps needed to manage their child’s “ambulatory” condition. These parents often find that they are not well enough supported by community health service providers and other necessary services to be able to offer the level of care their child requires within the home setting.

Providing an optimal level of continuity of care is a challenge for many of the most advanced health systems. There are many factors at work that keep hospitals and community services from developing an integrated, seamless network and continuum of services. Transition points from acute care to home are often difficult-for children, parents, hospitals and medical professionals inside the hospital and in the community. It is at these times in a child’s care that coordination often breaks down and critical gaps in service appear.

As a result, parents may need to go to the hospital emergency department to find reassurance and support or because the discharge planning has not been sufficient or successful. Illness and hospital re-admissions may result from complications arising from preventable lapses, omissions or errors in discharge planning and continuing care.

Things are slowly improving in health systems around the world. These transition challenges are increasingly being seen as opportunities that must and can be addressed and mitigated in projects and programs championed by groups of committed health professionals. Excellent examples, some referenced in this document, of continuing care network building do exist in BC across Canada and elsewhere, as the result of intensive efforts to improve dated discharge planning processes through the dedication, professionalism and persistence of key people in some of the world’s finest hospitals and health authorities. The learning that can be gained from these efforts provides a rich knowledge base of promising practices for designing program models that work better for the children and their families-and the professionals and their organizations as well.

This Project represents one such promising effort.

**Need for a Collaborative Model for Vancouver Island Aboriginal Children and Families**

As of the 2006 census, there were about 33,000 Aboriginal people on Vancouver Island living on and off reserve. The majority is composed of three groups of First Nations, the Coast Salish, Nuu-Cha-Nulth and Kwakwaka’wakw Nations. There are also Aboriginal and Métis people from other parts of BC and Canada.
The issues related to discharge planning for children with continuing care needs leaving acute care and the gaps in continuity of care for those children have a particular reality for Aboriginal families on Vancouver Island. Families and health professionals from Child Health BC (CHBC) the First Nations Health Council (FNHC) and Vancouver Island Health Authority (VIHA) identified the issues at meetings in Nanaimo at the Snuneymuxw First Nation Longhouse on October 8 & 9, 2009. As a result of service continuity gaps there are sometimes safety risks that can and do sometimes lead to health problems and preventable hospital readmissions.

The Snuneymuxw First Nation Longhouse meetings focused on why a program is needed and how it could be developed to work with Nanaimo General Hospital’s new Child and Youth Ambulatory Care Unit to improve current discharge processes, take advantage of the growing availability of specialized services closer to the child’s home environment and more effectively coordinate treatment received at BC Children’s Hospital and other specialized tertiary and pediatric care with family and community realities.

Child Health BC (CHBC) the First Nations Health Council (FNHC) and Vancouver Island Health Authority (VIHA) see these issues as a priority area and opportunity for a collaborative initiative. They have now partnered in a Project Planning Committee to champion, lead, design and demonstrate an improved and sustainable model for discharge planning that includes the essential components for successful family centred, culturally aware, continuing community care and support for these children and their families following discharge from hospital.

It is intended that this model be developed and agreed to by the Project Planning Committee, their respective organizations and the communities and then utilized in a model demonstration project with participating Aboriginal communities and families living in central and north Vancouver Island.

B.) PURPOSE OF THIS DOCUMENT

This document represents phase one of a Project consulting assignment. The activities as initially identified for this phase were to:

- Map the current discharge process so that duplication and gaps of services are identified.
- Identify contacts and positions that can build upon and leverage the role of hospitals in supporting the discharge planning.
- Identify how information flows between all interested parties and sectors such as BC Children’s Hospital, Vancouver Island Health Authority, and Aboriginal communities, etc.
- Gather information about the pediatric population described as needing chronic and/or complex care including discharges and follow-up from both inpatient and ambulatory services.
- Draft document incorporating the information gathered during the activities for review by the subcommittee.
Access to the subject matter experts and data that is necessary to complete descriptions of current state processes and information flows has been limited to date. Focus has therefore been on identifying potential key components of promising practices for developing the model, as will be required in subsequent Project phases.

This document is a draft for discussion and review by the Project Sponsor and Steering Committee for use in determining next steps. It is intended to outline and begin to build consensus on the key components required for this model demonstration Project to be successful. The document:

1. Outlines key issues related to the transition from hospital to home currently faced by Aboriginal children with complex care needs and their families as identified in this initiative
2. Offers some working definitions of key concepts
3. Outlines what is known (from initial available data) about the project target population
4. Presents a strategic change management model development framework
5. Identifies decisions to be made or confirmed regarding Project scope
6. Provides a high level overview of current BC Children’s Hospital discharge planning processes and information flows and potential gaps and offers some caveats in regard to the utility of mapping of current state processes
7. Reviews examples of promising practices and their key components
8. Recommends next steps

**Terminology**

The capitalized term “Project” is used here to describe the sum total scope of work. The terms “model” and “model demonstration project” are separate but related components of that Project. The model to be developed is a preferred or ideal set of goals, guiding principles, programs, activities, roles and accountabilities. This model may represent a longer-term state and a desired future level of maturity than may be feasible in a model demonstration project to be initiated in the near future. A “sustainable model” is one that is that is realistic, workable, achievable and demonstrably successful.

**Many Hands; One Circle**

The working title of the Project “Many Hands; One Circle” is offered to suggest the importance of strengthening human relationships in the face of fragmented systems. Whether the concept is integrated services, joined-up services, or wraparound services the fact is that solutions to persistent system disconnections are solved primarily through the efforts of teams of people with a shared commitment to improvement. The circle is also a profoundly important symbol in Aboriginal culture as it represents equality, interconnectedness, and continuity—all important elements of success for this Project. Circles are non-hierarchical and inclusive, and are one of the main tenets of Aboriginal worldview and belief systems. The title may also remind us of the need for the “Aboriginal Lens”, an ongoing critical success factor for this project.
C.) PURPOSE OF THE PROJECT

The purpose of this Project is to improve current hospital discharge planning processes and the continuity of care for Aboriginal children with complex care needs from central and north Vancouver Island. More specifically, this Project is to develop, on a demonstration basis, a sustainable model that:

1. Improves the current discharge planning processes and continuum of care and the relationship of those processes to other parts of the Health system;
2. Contributes to improved health and well being for those children and youth;
3. Responds to the identified issues facing Aboriginal children and youth with complex health needs and their families and communities;
4. Leverages the expanding availability of specialized services closer to the child’s home particularly those at Nanaimo General Hospital;
5. Coordinates efforts more effectively with the child’s family and with community agencies
6. Has been developed with the participation ownership, input and support of First Nations Health organizations, and the other key health institutions and health professionals whose efforts will be required for the Project’s success.

D.) PROJECT SCOPE

The Need for A Multiple-Lens, Integrated Perspective
The Project referred to in this document is the effort to develop a model and model demonstration project. It needs to integrate different perspectives to be most valuable. It has primarily been focused on discharge planning, which represents a certain hospital lens on the current situation. The health system lens could be better described as Continuity of Care-Managing Transitions from Hospital to Home.

The Aboriginal family and community lens is, “quite distinct from approaches focused on responding to the needs of the parents, family or community who ‘are receiving these children’. As a result, there is a strong, almost unavoidable need for a comprehensive integrated discharge program or strategy that includes linkages beyond what is normally delivered as part of the discharge planning process and as seen through the Aboriginal family’s lens”. (Aboriginal Children and Youth with Complex Health Care Needs: Aboriginal Parents and Health Workers Preparatory Session Snuneymuxw First Nation Longhouse on October 8 & 9, 2009, First Nations Health Council, Child Health BC and VIHA)

Determining Project Scope
This is a large subject matter with many potential dimensions of scope. Project scope decisions will need to:
a) Identify the potential range of issues related to the care and management of children with complex care needs that need to be addressed in a new and improved service delivery model and;
b) Establish clear, achievable priorities and key components to be addressed in the model demonstration project.

E. Identified Issues Facing Aboriginal Children with Complex Care Needs and their Families on Vancouver Island

There are three types of issues that reflect the community and health care professionals perceptions captured in the Snuneymuxw First Nation Longhouse document. They are summarized below:

A. Support to Family Care Givers

<table>
<thead>
<tr>
<th>IDENTIFIED ISSUES</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Health professionals and service providers need to be more engaged in ongoing meaningful supportive relationships with parents/caregivers of children with complex care needs. Parents/caregivers need to be better heard and assisted to make decisions regarding their child’s situation and the many kinds of challenges they are now confronting and will be dealing with for an indefinite period—often far away from those professionals and services.</td>
</tr>
<tr>
<td>• There is a need for more ongoing contact, communication and support to “cobble together” an effective support system for the child and family both in the community and between the home and the available services/facilities—before, during and after the stay in hospital.</td>
</tr>
<tr>
<td>• Health professionals and service providers need to design and provide their services in recognition of the effects of poverty on the ability of parents, families and communities to meet the needs of children with complex health needs.</td>
</tr>
<tr>
<td>• Health professionals and service providers need to recognize and help address, as part of their programs, the ongoing need for transportation, lodging, child care supports and other essential components that help with the transitions back and forth from the home to wherever the required specialized and follow up care is available.</td>
</tr>
</tbody>
</table>

B. Access to Services

<table>
<thead>
<tr>
<th>IDENTIFIED ISSUES</th>
</tr>
</thead>
<tbody>
<tr>
<td>• There is a serious lack of access in some parts of Vancouver Island, (as well as equally limiting perceptions of inaccessibility in other parts) to services for dealing with children with complex health needs, little choice about what services to access, and difficulties accessing what services are available.</td>
</tr>
<tr>
<td>• When needs arise outside of normal working hours, particularly when it could be an emergency situation, these challenges are exacerbated.</td>
</tr>
<tr>
<td>• There are challenges/gaps in cross cultural/cultural awareness which impede access to existing services</td>
</tr>
</tbody>
</table>
C. Insufficient Teamwork, Priority and Service Coordination

<table>
<thead>
<tr>
<th>IDENTIFIED ISSUES</th>
</tr>
</thead>
<tbody>
<tr>
<td>• The combined impact of organizational disconnections, busy people, a lack of team structures, team roles, a single responsible point of contact and coordination and system level accountabilities and follow-up across the health system and between health and social, education and other service is multiplied when that child and family live in a physically and culturally isolated Aboriginal community.</td>
</tr>
<tr>
<td>• There is no comprehensive integrated discharge program or strategy that includes linkages beyond what is normally delivered as part of the hospital discharge planning process and as seen through the Aboriginal family’s lens.</td>
</tr>
<tr>
<td>• Quality control of key processes including identification of Aboriginal children, discharge planning and follow up of children and families from hospital to community; related communication, information sharing, tracking, monitoring and child health outcome and program evaluation is not sufficient to optimize the health and well being of the most vulnerable children in Vancouver Island Aboriginal communities</td>
</tr>
</tbody>
</table>

F.) VANCOUVER ISLAND ABORIGINAL CHILDREN DISCHARGED FROM BC CHILDREN’S HOSPITAL AND SUNNYHILL

The table in Appendix II indicates the total number of children discharged from BCCH and Sunnyhill to Vancouver Island with the child’s last home address by region of Vancouver Island (494) in fiscal year 2008-09. The conditions causing admission by most responsible specialty are:

- Surgical (139),
- Oncology (129)
- Endocrinology/Gastroenterology/Hematology/Nephrology and Other Medical Specialties- (56)
- Cardiac Sciences- (50)
- General Pediatrics- (41)
- Neurological Sciences- (40)
- Critical Care- (21)
- Developmental Pediatrics- (14)
- Mental Health- (4)

There is no data on Aboriginal children readily available, as they are not identified upon admission or discharge.

(Note: Additional sources of available data are being pursued).

G.) DOCUMENTING CURRENT AND FUTURE DISCHARGE PLANNING PROCESSES

In an effort to understand how current general hospital discharge processes work it is considered useful to begin by drawing a process flow chart or information flow map. In such
efforts, when asking several doctors, nurses, or social workers involved in discharge planning to describe the process, it is not unusual to find that:

- There is no consensus on what the current process is
- There are many methods utilized by different individuals
- There is widespread process and quality variation
- There is no standard operating procedure

*Creating a Lean Six Sigma Hospital Discharge Process: A Six Sigma Case Study, six sigma .com*

While a detailed flow chart of the current discharge processes is a desirable product it will be more time consuming than can be accommodated in this phase of the project and will need to involve those who play a role in the discharge planning. That circumstance has not been available to date in this Project. It is also a potentially contentious process and can be perceived as threatening or critical of incumbent staff if not conducted through a well-managed internal clinical team-led procedure review process or as a university research project.

The research goals of one current example— is a Canadian (Memorial University) mixed-method research study that focused on the care providers and included:

1. Identifying the critical patient information requiring communication amongst care providers along the continuum care;
2. Describing current communication practices for communicating critical patient information across the acute and community care settings;
3. Providing insight into the effect of these communication practices on the likelihood of preventable, post-discharge adverse events;
4. Identifying best practices for enabling effective communication amongst providers across care settings.

This study involves: (1) acute care providers; (2) discharge planning nurses; and (3) community health nurses. It appears to have focused more on mapping the desired communication pathways than the actual or current processes. The first part of this study entailed a broad survey of providers across care settings, while the second part entailed focus groups meant to bring providers from all settings together to develop a best practice model for communicating critical discharge planning information. *(Heather Predham, The Influence Of Provider-To-Provider Communication Practices On The Occurrence Of Preventable Post-Discharge Adverse Events: A Study Of Acute And Community Care Professionals in the Newfoundland Eastern Regional Integrated Health Authority, Canadian Patient Safety Institute Website, 2010)*

**Implications for this Project**

It is suggested here that a detailed flowchart of the desired future process is a more important, engaging and productive starting point followed by a strategy to migrate to that state than a detailed (or overly generalized) description of current processes. Using that desired state as the working standard, the existing gaps and potential overlaps as well as problematic information flow can be identified and addressed as part of the movement toward achieving desired information and communication pathways. (In an analogous example, from this writer’s experience, it is more important, and urgent, as a first step, to determine the desired standards
for re-processing medical devices than it is to survey and document all the many ways staff in hospitals clean them today. We know it is generally problematic. The plan for how each hospital will migrate, as they determine is required, from current methods to the desired future standard is the subsequent step of most value.)

A key next step for this Project is to determine who is needed (as members of a working group) to map the actual discharge planning-care continuity process to be used in the Model Demonstration project. Ideally, those who will be asked to utilize the redesigned process should be engaged or consulted in its design.

There are apparently significant risk factors and gaps in some aspects of discharge planning and discharge processes at BCCH and therefore timely opportunities for improvement within the scope of this Project. There are also exemplary discharge planning and continuity of care processes in use.

**H.) IDENTIFYING KEY COMPONENTS OF PROMISING SERVICE CONTINUITY MODELS FOR CHILDREN WITH COMPLEX HEALTH CARE NEEDS**

The following table is summary of a preliminary examination of some of the available literature and the learning from experience in various efforts to improve the continuity and quality of care between hospital and home for children with complex care needs and their families. These suggested Key Components are derived from the reviewed reference sources. The fuller review of these individual documents is provided in Appendix I.

<table>
<thead>
<tr>
<th>Reference</th>
<th>Key Components/Promising Practices</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1. Pediatric Complex Care Collaborations Community Care Literature Review</strong></td>
<td>A Program&lt;br&gt;Trained and supported Discharge/Community Care Planners&lt;br&gt;Trained GP’s&lt;br&gt;Education and information for clinicians, families and patients&lt;br&gt;A Prime Worker/Integrated Case Coordinator&lt;br&gt;A Family Centred Team Approach&lt;br&gt;Discharge case conferencing, coordination and planning&lt;br&gt;Team Building Opportunities&lt;br&gt;Team Accountabilities: individualized care plans should be developed and signed&lt;br&gt;Network Building Opportunities</td>
</tr>
<tr>
<td><strong>2. Norman Saunders Complex Care Initiative, Sick Kids Hospital, Toronto, 2010</strong></td>
<td>A Complex Care Team:&lt;br&gt;A Written Care Plan/Electronic and written ‘medical passport’&lt;br&gt;Community Alliances&lt;br&gt;Virtual Outpatient Care&lt;br&gt;Health-Care Coordination Plan&lt;br&gt;Sick Kids would be a hub to peripheral hospitals and community health-care workers</td>
</tr>
<tr>
<td><strong>3. Pediatric Complex</strong></td>
<td>Design criteria for entry rather than defining complex care</td>
</tr>
</tbody>
</table>
| Care Coordination Project- Children’s Hospital of Eastern Ontario | Designated coordinator/navigator  
Electronic Health Record (or equivalent)  
Most Responsible Physician  
A process for convening client/family and care providers  
Clear roles-understanding of each partners role in care  
Standardized documentation for family |
|---|---|
| 4. Community Capacity Building for Technology Dependent Children, BC Children’s Hospital | Collaboration is seamless from hospital to local team  
Education and training of care providers and family  
Ongoing support from BCCH by phone, Clinics,  
Assistance with supplies and equipment,  
Follow-up with specialists continuing education |
| 5. Community Family Centred Care for Children with Complex Medical Needs Integrated Children’s Services Team, Winnipeg, | A Lead Service Coordinator (LSC)  
The LSC is either a nurse from the WRHA or a Social Worker from CSS.  
The LSC has a “buddy” of the other discipline for each child on its caseload.  
The LSC can access services provided by both HC and CSS.  
A Family Centred Approach is used in service delivery.  
Extensive range of activities and services included in Program Model  
Interface of the medical model (which focus on achieving medical stability for the child) and family centred practice model (which ensures that family is central in all planning that occurs regarding the needs of their child and family) provides a balanced perspective for families and care providers. |
-Partnerships, Linkages and Collaboration;- (Discharge Planning, Transition Teams, Programs, Positions)  
-Continuity of Care; (Outreach and Support, Specialized and Traveling Clinics and Services)  
-System-level Strategies (Common Assessment and Intake, Service Integration and Coordination, Government Initiatives |
| 7. Pediatric Medical Home Learning Collaborative Initiative, Report to the Minnesota Legislature 2010, Minnesota Department of Health, January 2010 | Developing trusting relationships with patients and families  
Partnering with and learning from patients and families  
Using a team approach for the care of chronic conditions,  
Ensuring and measuring that patients/families, providers and clinic staff are satisfied with the care provided;  
Working continuously on quality improvement;  
Focus on outreach recruitment and promotion,  
Promote collaborative learning,  
Use experienced teams as mentors,  
Identify and overcome resource barriers including compensation for additional medical activities. |
| 8. Treaty 7 Discharge | A Treaty 7 Liaison Coordinator was hired to assist in the development of a protocol for the |
Many Hands; One Circle, February 10, 2011

Protocol, Calgary
Discharge planning process, to support transition to home in First Nation communities. Alberta Children’s Hospital (ACH) described the comprehensive process and information sharing it does with First Nations providers, to ensure that all health care needs are coordinated, upon discharge. Build rapport through options such as face to face interactions, videoconferencing, and job shadowing.

Use of standardized tools and processes
Individualized plans that promote continuity of care across primary, acute and community services
Multi-disciplinary and multi-agency collaboration
Discharge planning is part of a continuing process not an event
The process is a team effort led by a named coordinator
It happens at admission
It centres on and involve the patient in the planning
That it is assessed and evaluated from safety, quality and risk management perspectives
Indicators provide performance benchmarking across the jurisdiction and others
A shared vision, definitions,
A standardized flowchart or pathway
Documentation of best practices and tools
Staff education and training standards
Consumer/carer information material
Best practice standards to ensure “acceptable standards” are met.

10. Hospital Discharge, Up To Date Online Website, September 2010
Clinician, pharmacist telephone calls to patient/family
Early post-discharge follow-up
Home visits
Tele-monitoring
Multiple interventions by interdisciplinary team
Plain language information

Discharge Planning Functions, Standards and Guidelines
An additional table is provided below which illustrates two approaches from two jurisdictions (Canada and Australia) to identifying discharge planning functions and the respective standards and guidelines where available. The functions have been named and provided by the Project consultants to organize the material.

SAMPLE DISCHARGE PLANNING FUNCTIONS AND STANDARDS FOR COMPARISON PURPOSES

<table>
<thead>
<tr>
<th>Function within the Discharge Planning Process</th>
<th>Benchmark Standard #1 (Canadian Association of Discharge Planning and Continuity of Care 1995)</th>
<th>Benchmark Standard # 2 (Queensland Health, Australia: Guidelines for Pre-admission, Discharge Planning and Transitional Care, 1999)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Documentation of Current Policies and Standards</td>
<td>“Discharge planning is a process that includes identification, assessment, goal setting, planning, implementation, coordination and evaluation”</td>
<td>“To achieve quality patient care, discharge planning should be an integral part of routine health service care (with) formal policy and well defined procedures.”</td>
</tr>
<tr>
<td>Early Planning for Discharge</td>
<td>Promote early identification and assessment of patients requiring assistance with planning for discharge</td>
<td>Processes during pre-admission, should assess social and financial issues and community services needs which need to be attended to.</td>
</tr>
<tr>
<td>-----------------------------</td>
<td>-------------------------------------------------------------------------------------------------</td>
<td>----------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Collaborative planning</td>
<td>Collaborate with the patient, family and health care team to facilitate planning for discharge.</td>
<td>Patients (and care-givers) are the primary focus of care and participate in decisions about their health care, including discharge planning.</td>
</tr>
<tr>
<td>Referral</td>
<td>Recommend options for the continuing care of the patient and refer to programs or services that meet the patient's assessed needs and preferences. Liaise with community agencies and care facilities to promote patient access and to address gaps in service.</td>
<td>The Health District is responsible for providing or arranging the provision of transitional care following hospitalization, sufficient to ensure the patient’s recovery from an acute phase of treatment... Transitional care flows from acute care, giving a sense of continuity ...</td>
</tr>
<tr>
<td>Family Support</td>
<td>Provide support and encouragement to patients and families during the stages of assessment and discharge from the hospital</td>
<td>Patients (and carers) are the primary focus of care and participate in decisions about their health care, including discharge planning.</td>
</tr>
<tr>
<td>Program Accountability</td>
<td>N/A</td>
<td>Accountability processes are in place to evaluate and improve discharge planning.</td>
</tr>
<tr>
<td>Joint Workforce Training</td>
<td>N/A</td>
<td>Joint workforce training is implemented to improve acute and community services across the care continuum</td>
</tr>
<tr>
<td>Information Sharing</td>
<td>N/A</td>
<td>Patient information is made available to all relevant care providers in an efficient and timely manner.</td>
</tr>
<tr>
<td>Involvement of General Practitioner and other Hospitals</td>
<td>N/A</td>
<td>The patient’s general practitioner and local hospitals close to home are involved across the episode of care.</td>
</tr>
<tr>
<td>Capacity to Serve Aboriginal People is Developed</td>
<td>N/A</td>
<td>N/A</td>
</tr>
</tbody>
</table>
I.) NEXT STEPS

This draft document is intended to facilitate the following next steps with the Project Planning Committee whose context and subject matter expertise is required to:

1. Review and discuss the relevance of material presented and other requirements
2. Determine the vision of the Project
3. Determine the scope of the Project
4. Determine Project roles and responsibilities
5. Determine the key components of the Model
6. Determine the input required for mapping the model Discharge Process/Care Continuity process

A meeting with the Planning Committee will be useful to address these steps.
APPENDICES
# Appendix I: Some Examples of Promising Practices

<table>
<thead>
<tr>
<th>Context</th>
<th>Review of last 15 years of journal articles government papers and reports via the Internet.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Purpose</td>
<td>To improve patient and family health outcomes and improve collaboration across the health care settings by providing a framework for an enhanced model of care for children with complex medical needs coordinated across multiple care providers and health sectors</td>
</tr>
<tr>
<td>Issues</td>
<td>The gap in service provision creates pressure on the pediatric hospitals to continue the total management of these children, not just the tertiary component. For most tertiary care episodes, there is a trend in reduced lengths of hospital stay and earlier discharges. Patients are leaving hospital with greater complexities and chronic conditions than ever before. GPs have become de-skilled due to children’s hospitals and unit staff delivering many aspects of primary care within the hospital setting.</td>
</tr>
<tr>
<td>Promising Practices/ Models</td>
<td>‘Medical Home’ model in US for children with multiple medical complexities to maximize the potential of the patients and families by meeting their health needs in the home care setting. Homecare can deliver innovative, integrative, interdisciplinary partnerships. Individual care plans as well discharge summaries facilitated through a coordinated pediatric community program improves communication and information exchange amongst tertiary and community care providers. Supported by communication pathways, a shared clinical care summary utilizing an electronic database</td>
</tr>
</tbody>
</table>
| Key Components for Successful Models | - A Program: The implementation of a coordinating program will improve the effectiveness of services and support parents with the care of their child including:  
- Trained supported Discharge/Community Care Planners  
- Education and information for clinicians, families and patients  
- A Prime Worker/Integrated Case Coordinator  
- Discharge case conferencing, coordination and planning  
- A Family Centred Team Approach  
- Team Building Opportunities  
- Team Accountabilities: individualized care plans should be developed and signed  
- Network Building Opportunities |
### 2. Reference: Norman Saunders Complex Care Initiative, Sick Kids Hospital, Toronto, 2010, (Service Integration Innovation Award, Ontario Ministry of Health)

| Context | A child with eight different medical problems, may be treated by eight distinct sub-specialists, requires home care, has school issues and falls sick continuously. These children are a growing diverse group with diagnostic conditions that are individually rare but collectively relatively common, have multiple health needs, requiring multiple services from multiple sectors in multiple locations. |
| Purpose | The initiative will define who falls into the category of complex care, what families need in order to cope and how services can best be delivered. Goal: to ensure families can receive excellent care locally, and be spared the disruption, expense, and inconvenience of frequent visits to Sick Kids. |
| Issues | Care coordination if not optimized can lead to poor child- and family-centred health outcomes. |
| Approach | The Initiative team will treat families in this new model of care and conduct research to improve the lives of the children and families with medically complex conditions. |
| Key Components for Successful Models | The innovations being introduced at Sick Kids are geared toward family empowerment, and include: |
| | A Complex Care Team: a new development on the in-patient ward; run by a nurse practitioner and a physician provides continuity of care for that child. |
| | A Written Care Plan: When ready to go home, the family meets with a nurse practitioner to review their needs and multiple sub-specialists they will need to keep in contact with; a ‘care plan,’ an electronic and written ‘medical passport’ for the child is provided, to keep all involved in the child’s care ‘in the loop’. |
| | Community Alliances: alliance with the Community Care Access Centres (CCAC), community physicians and community hospitals to ensure that families are getting the services they require and deserve in their home and in their community. |
| | Virtual Outpatient Care: makes complex care team accessible to health-care providers and parents outside the Hospital setting. Families can communicate by clinic visits, phone and/or email, and get rapid answers. This program promotes continuity in treatment, prevents crises and reduces need for hospitalization and ER visits. |
| | Heath-Care Coordination Plan: Working with the other health-care providers in the Hospital and the community, we help develop a coordination plan. Sick Kids would be a hub to peripheral hospitals and community health-care workers. |
| Evaluation | A study will evaluate a newly developed targeted intervention aimed at providing integrated community-based care coordination in collaboration with a tertiary care children’s hospital focusing on the effectiveness and efficiency of this intervention for a variety of outcomes including child, parent and family well-being, and the efficiency of health-care delivery to these children. One key outcome being examined is how the “family-centred care” provided to families is working- are they more likely to comply with treatments, come back for follow-up treatments and have less frustration? |
### Context
Absence of mechanisms to share data and identify complex care clients
Unable to identify whether there is an overlap of clients between CHEO and community partners; Organizations are working in silos
Clients are navigating on their own
Processes are not client focused

### Purpose
Client/Family centred care
Improved overall satisfaction
Improved health status and outcomes
Reduced ED visits
Reduced events of hospitalization
Reduced length of stay

### Issues
Difficult to define complex care
Transitions between care in hospital and care in community and from paediatric to adult care
Parents coordinating care
Difficulty accessing services and who to contact
No one to advocate on behalf of client
Absence of electronic health record

### Approach
Develop a definition of complex care
Identify the number of clients potentially at risk in the Ottawa region
Profile a select number of clients and identify gaps in service and issues
Review current literature, resources, models and best practices in other region
Generate recommendations for strengthening the local system’s capacity to support children and youth with complex needs, and their families.
Develop a coordinated model of care for the region.

### Key Components of Promising Practices for Successful Models
- Design criteria for entry rather than defining complex care
- Designated coordinator/navigator
- Electronic Health Record (or equivalent)
- Most Responsible Physician
- A process for convening client/family and care providers
- Clear understanding of each partner’s role in care
- Standardized documentation for family

### Pilot
Client group of 20 -25 with staggered entry
18 month period
Confirm structures and assumptions about lead case manager
Host organization driven by client needs
Assess EHR requirements

### Evaluation
Formally assess satisfaction of clients and family

---

4. Reference: Community Capacity Building for Technology Dependent Children
Lisa Kwong, RN
Erin Chassie, RT
Astrid St.Pierre, OT
Home Tracheostomy & Ventilation Program
BC Children’s Hospital

### Context
Growing population of children with chronic airway/ventilation problems requiring technology
<table>
<thead>
<tr>
<th>Purpose</th>
<th>Closer to home excellent care</th>
</tr>
</thead>
</table>
| Issues  | Shortened hospitalizations, increased acuity, increased complexity, increased burden on the family, increased expectations of community services  
Limited resources, Lack of experience, difficult to build expertise due to limited number in each community  
Labour intensive program is required |
| Approach| Hospital, Home and Community Transition team customized for each child and family |
| Key Components of Promising Practices for Successful Models | A defined program  
A defined team  
Family supports with accessing and costs of equipment and supplies  
Collaboration is seamless between players-Weaning from hospital to local team  
Education and training of care providers and family  
Ongoing support from BCCH by phone, clinics, assistance with supplies and equipment, follow-up with specialists continuing education  
A program outreach and clinical coordinator  
A local prime case manager  
A local accessible clinic or physician |
**Context**
Children’s Special Services in Winnipeg and Pediatric Home Care have worked together cooperatively for many years to provide services for children with complex medical and developmental needs. In 1995 Unified Referral and Intake System (URIS) Program was created to provide a standard means of classifying the complexity of health care procedures and to establish the level of qualification required by staff to support each child. (URIS) is a joint strategy developed by the departments of Family Services, Health and Education and Training. Part of a major government initiative to integrate health and social services in Winnipeg.

**Purpose**
Service integration

**Issues**
The children in this population have a wide range of physical/medical and developmental needs. These children are often chronically ill, medically fragile and dependent on technology.

**Approach**
Integration of two teams (CSS and WRHA Pediatric Home Care) who both provide support for families parenting a child with complex medical and developmental needs.
Blending of the Medical Model with Family Centred Practice
Community based with strong linkages to medical and social systems
Social Workers and Nurses are part of the same team. Families access both Social Work and Nursing support through one system.
Relationship building/developing partnerships with families to meet family needs. Helping families to recognize and build informal support systems (extended family, friends, community organizations).

**Key Components of Promising Practices for Successful Models**
A Lead Service Coordinator (LSC) is assigned to work with the family to assist and support them in coordinating services for their family.
The LSC is either a nurse from the WRHA or a Social Worker from CSS.
The LSC has a “buddy” of the other discipline for each child on its caseload.
The LSC can access services provided by both HC and CSS.
A Family Centred Approach is used in service delivery.
Extensive range of activities and services included in Program Model
Interface of the medical model (which focus on achieving medical stability for the child) and family centred practice model (which ensures that family is central in all planning that occurs regarding the needs of their child and family) provides a balanced perspective for families and care providers.

**Evaluation**
Building expertise in finding “paths of service” to meet the needs of families parenting children with complex medical and developmental needs.
Continuing to explore and develop “best practices” to better meet the needs of families. (E.g. Early Intervention Programs are developing expertise in approaches/intervention for children with complex needs.)
| **Context** | To continue to stimulate discussion and to initiate a national dialogue on what’s working and why. It should not be viewed as a comprehensive compendium of all promising or best practices |
| **Purpose** | Presents a “snapshot” of some of the promising practices that are currently in place across Canada. |
| **Issues** | In our current fragmented system, transitions points are especially difficult; it is often at these times in a child’s care that coordination breaks down and critical gaps in service appear. |
| **Approach** | Describes some of the promising practices currently in place throughout the country. Based on discussions with parents and providers, the factors that support and those that impede continuity of care are analyzed. |
| **Key Components of Promising Practices for Successful Models** | Four broad themes emerged to describe promising practices:
- Communication and Capacity-building; (Information Transfer, Telehealth, Telemedicine, Training and Education, Protocols, Clinical Pathways, Care Maps)
- Partnerships, Linkages and Collaboration; (Discharge Planning, Transition Teams, Programs, Positions)
- Continuity of Care; (Outreach and Support, Specialized and Traveling Clinics and Services)
- System-level Strategies (Common Assessment and Intake, Service Integration and Coordination, Government Initiatives) |
### 7. Reference: Pediatric Medical Home Learning Collaborative Initiative, Report to the Minnesota Legislature 2010, Minnesota Department of Health, January 2010

| Context | The pediatric medical home initiative results from federal grants. The learning collaborative began in the spring of 2004 with eleven (11) pediatric clinic teams and ended in May of 2009 with thirty-six (36) pediatric and family practice clinic teams participating serving children and youth based on the health care condition, duration, and impact. |
| Purpose | Intended as a quality improvement effort to implement medical home as a standard of care for children with special health care needs and ultimately a standard of care for all children. |
| Issues | A lack of buy-in or support from other staff or administration, Lack of available staff or dedicated time to do additional activities, Issues related to funding or billing for additional activities, and logistical issues. |
| Approach | The American Academy of Pediatrics defines medical home, as “a model for caring for children with special health care needs in which the primary care provider’s role is to make sure patients’ care is coordinated and effective.”  
Involves patients and their families as partners in care and in clinic quality improvement. It links medical and community resources while striving to take the principles of primary care (care that is accessible and focused on the patient for the long term) a step further in order to improve care quality, patient experience, and health outcomes.  
Adds practice-based quality improvement processes that are continuous, linked to and coordinated with community resources (schools, early childhood screening programs, mental health providers, etc.) and office systems that track progress and measure outcomes.  
Improves the way individual clinicians and clinic systems work with and meet the needs of children and youth with chronic, complex health conditions or disabilities. |
| Key Components of Promising Practices for Successful Models | Developing trusting relationships with patients and families  
Partnering with and learning from patients and families  
Using a team approach for the care of chronic conditions, ensuring and measuring that patients/families, providers and clinic staff are satisfied with the care provided; working continuously on quality improvement; focus on outreach recruitment and promotion, promote collaborative learning, use experienced teams as mentors, identify and overcome resource barriers including compensation for additional medical activities. |
| Evaluation | Providers were able to improve the quality of various aspects of their practices. Changes were statistically significant in nearly every area measured by the Medical Home Index.  
Providers felt that parent participation on their teams was a critical component to implementing effective Quality Improvement strategies.  
Parents, even those not involved in medical home teams, noticed improvements in services provided to their families and children with special health care needs.  
Parents who participated on Medical Home teams reported an increased ability to advocate for their child and issues related to children with special health care needs in their schools and communities. |
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<tr>
<td><strong>Context</strong></td>
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<td><strong>Purpose</strong></td>
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<tr>
<td><strong>Issues</strong></td>
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<tr>
<td><strong>Approach</strong></td>
</tr>
<tr>
<td><strong>Key Components of Promising Practices for Successful Models</strong></td>
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<tr>
<td><strong>Evaluation</strong></td>
</tr>
</tbody>
</table>
The Treaty 7 Calgary Health Region Discharge Process Algorithm (a description of a process that completes some sequence of operations), which is a graphic representation of the “ideal” process documented in the protocol agreement, is provided below.
**9. Australian Capital Territory, Discharge Policy, Health, 2006**

<table>
<thead>
<tr>
<th>Context</th>
<th>Requirement to improve discharge practices supported by national legislation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Purpose</td>
<td>To provide ACT Health services with a framework for shaping discharge-planning practices based on current best practice.</td>
</tr>
<tr>
<td>Issues</td>
<td>The identified need for streamlined, consistent and recognizable processes, documentation and consumer information across the health portfolio</td>
</tr>
<tr>
<td>Approach</td>
<td>Provides principles and lists guidelines</td>
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**Key Components of Promising Practices for Successful Models**

<table>
<thead>
<tr>
<th>ACT Principles for Discharge Planning promote:</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Use of standardized tools and processes</td>
</tr>
<tr>
<td>• Individualized plans that promote continuity of care across primary, acute and community services</td>
</tr>
<tr>
<td>• Multi-disciplinary and multi-agency collaboration</td>
</tr>
<tr>
<td>• The concept that discharge planning is part of a continuing process not an event</td>
</tr>
<tr>
<td>• The concept that the process is a team effort led by a named coordinator</td>
</tr>
<tr>
<td>• That it happens at admission</td>
</tr>
<tr>
<td>• That it must centre on and involve the patient in the planning</td>
</tr>
<tr>
<td>• That it is assessed and evaluated from safety, quality and risk management perspectives.</td>
</tr>
</tbody>
</table>

Future ACT “best practice guidelines” for implementation of the Policy will include:

<p>| • A shared vision |
| • Definitions |
| • A standardized flowchart or pathway |
| • Documentation of best practices and tools |
| • Staff education and training standards |
| • Consumer/carer information material |
| • Best practice standards to ensure “acceptable standards” are met |
| • Performance indicators to provide performance benchmarking across the jurisdiction and against other jurisdictions |</p>
<table>
<thead>
<tr>
<th>10. Hospital Discharge, V18.3 Eric Alper et.al., UpTo Date Online Website, September 2010</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Context</strong></td>
</tr>
<tr>
<td><strong>Purpose</strong></td>
</tr>
<tr>
<td><strong>Issues</strong></td>
</tr>
</tbody>
</table>
| **Key Components of Promising Practices for Successful Models** | • Clinician, pharmacist telephone calls to patient/family  
• Early post-discharge follow-up  
• Home visits  
• Tele-monitoring  
• Multiple interventions by interdisciplinary team  
• Plain language information |
### Appendix II: VIHA Residents-BCCH & SunnyHill Inpatient Discharges, 2008/2009

#### Developmental Peds  General Peds  Endocr/Gastro/E Hemat/Neph/ Other MedSpec  Oncology  Cardiac Sciences  Critical Care  Neuro Sciences  Surgical  Mental Health  Total Discharges

<table>
<thead>
<tr>
<th>ATA</th>
<th>Most Responsible Doctor Specialty</th>
<th>Developmental Peds</th>
<th>General Peds</th>
<th>Endocr/Gastro/E Hemat/Neph/ Other MedSpec</th>
<th>Oncology</th>
<th>Cardiac Sciences</th>
<th>Critical Care</th>
<th>Neuro Sciences</th>
<th>Surgical</th>
<th>Mental Health</th>
<th>Total Discharges</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>14</td>
<td>41</td>
<td>55</td>
<td>139</td>
<td>50</td>
<td>21</td>
<td>40</td>
<td>139</td>
<td>4</td>
<td>494</td>
</tr>
</tbody>
</table>

#### Unplanned Re-Admits - Same or Related Dx

<table>
<thead>
<tr>
<th>Inpatient readmit &lt;= 7 days (prev acute visit)</th>
<th>Inpatient readmit 8-28 days (prev acute visit)</th>
</tr>
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<tbody>
<tr>
<td>NAV</td>
<td>NAV</td>
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</table>

| Discharges by HSDA / LHA                      |                                              |
|-----------------------------------------------|                                              |
| South Vancouver Island HSDA                   |                                              |
| Greater Victoria LHA                          | 5                                             |
| Sooke LHA                                     | 4                                             |
| Saanich LHA                                   | 2                                             |
| Gulf Islands LHA                              | 1                                             |
| Central Vancouver Island HSDA                 | 9                                             |
| Cowichan LHA                                  | 1                                             |
| Lake Cowichan LHA                             | 1                                             |
| Ladysmith LHA                                 | 3                                             |
| Nanaimo LHA                                   | 3                                             |
| Qualicum LHA                                  | 3                                             |
| Alert LHA                                     | 4                                             |
| North Vancouver Island HSDA                   | 0                                             |
| Courtenay LHA                                 | 3                                             |
| Campbell River LHA                            | 4                                             |
| Vancouver Island West LHA                    | 1                                             |
| Vancouver Island North LHA                   | 6                                             |
| South Vancouver Island HSDA                   | 36%                                           |
| Greater Victoria LHA                          | 29%                                           |
| Sooke LHA                                     | 0%                                            |
| Saanich LHA                                   | 7%                                            |
| Gulf Islands LHA                              | 0%                                            |
| Central Vancouver Island HSDA                 | 64%                                           |
| Cowichan LHA                                  | 7%                                            |
| Lake Cowichan LHA                             | 0%                                            |
| Ladysmith LHA                                 | 7%                                            |
| Nanaimo LHA                                   | 21%                                           |
| Qualicum LHA                                  | 7%                                            |
| Alert LHA                                     | 29%                                           |
| North Vancouver Island HSDA                   | 0%                                            |
| Courtenay LHA                                 | 0%                                            |
| Campbell River LHA                            | 0%                                            |
| Total Discharges                              | 494                                           |

| Total Discharges                              | 494                                           |
|                                               |                                               |

|Italic Notes:** Includes all burns, i.e. any hypertensin, all degrees, any TIA (surface area) Internal Care: *Please refer to separate worksheet for 'SunnyHill critical care'** AIMS - any case regardless of amount of time spent on ECMO Cardiac Ventilation - includes any case where patient is on invasive positive pressure ventilation, regardless of time spent on ventilator. Unplanned Related readmits performed in the main P.O. location for any doctor specialty, or without anesthesia.

*Unplanned Related readmits performed in the main P.O. location for any doctor specialty, or without anesthesia.
Appendix III: Key Concepts and Definitions

a) Complex Care:

- “Children with complex health care needs are those with complex physical, developmental and/or mental health care needs requiring frequent transitions between levels of care and services”.

- “Children and youth with special health care needs are defined as having or being at increased risk for having a chronic physical, developmental, behavioral, or emotional condition that requires health and related services of a type or amount beyond that required by children generally.”

- “Patients having a chronic physical, developmental, behavioral and/or emotional condition who require greater than usual levels of health care include patients requiring:
  - Involvement from multiple specialized clinics
  - Specialized multi-disciplinary team management
  - Frequent hospital admissions/appointments
  - Psychosocial support and with complex socioeconomic needs
  - Assistance with chronic health conditions (diagnosed and undiagnosed)
  - Additional health care and educational resources to facilitate their support in the community, i.e. rural and remote patients.”
  *(Chronic/Complex Care Discharge Clinical Practice Consultant Women’s and Children’s Hospital, South Australia, 2010)*

*(Note: One Demonstration Project summarized below suggests that defining criteria for program entry is more useful than efforts at defining complex care)*

b) Continuity of Care

- “The extent to which health care services over time are perceived (by service providers and third parties) as a coherent and connected succession of events consistent with a patient’s medical needs and personal context.

- How one patient experiences care over time as coherent and linked; this is the result of good information flow, good interpersonal skills, and good coordination of care.

- Occurs when separate and discrete elements of care are connected and when those
elements of care that endure over time are maintained and supported.

• There are three types of continuity:
  o **Informational continuity** means that information on prior events is used to give care that is appropriate to the patient’s current circumstance.
  o **Relational continuity** recognizes the importance of knowledge of the patient as a person; an ongoing relationship between patients and providers is the undergirding that connects care over time and bridges discontinuous events.
  o **Management continuity** ensures that care received from different providers is connected in a coherent way. Management continuity is usually focused on specific, often chronic, health problems.


c) Discharge Planning

• “Effective discharge planning enables smooth movement across sectors, promotes inter-organizational collaboration and develops the families’ skills and capacity to care for their children at home”.
• Social workers engaged in discharge planning coordinate discharges for patients by collaborating with the patient, family, health care team and community resources. The social worker is involved with the early identification and assessment of the patient’s needs and implements timely discharge plans that result in continuity of care and efficient use of hospital and community resources.

• Discharge planning is a process that includes identification, assessment, goal setting, planning, implementation, coordination and evaluation.

*(The Association of Discharge Planning Coordinators of Ontario (ADPCO). Hospital Discharge Planning: A Balancing Act, May 1997).*

• “In order to coordinate timely discharge plans, the social worker uses the discharge planning process to:
  o Promote early identification and assessment of patients requiring assistance with planning for discharge.
  o Collaborate with the patient, family and health care team to facilitate planning for discharge.
  o Recommend options for the continuing care of the patient and refer to accommodation, programs or services that meet the patient’s assessed needs and preferences.
  o Liaise with community agencies and care facilities to promote patient access and to address gaps in service.
  o Provide support and encouragement to patients and families during the stages of
assessment and discharge from the hospital”.

(The Canadian Association of Discharge Planning and Continuity of Care (CADPACC): Guidelines and Standards for Discharge Planning Coordinators, 2006)

- “Discharge planning process is the coordination of client discharge through collaboration between members of the inter-professional health care team; patients and families.
- The Discharge Planning process assists in early identification and assessment of the client’s needs, and implements timely discharge plans along an integrated continuum of care.
- The process ensures efficient utilization of hospital and community resources. Discharge planners are qualified health care professionals who ensure the consistent application of the discharge planning process including the early identification, assessment, goal setting, planning, implementation, coordination, and evaluation”

(Position Statement, Association of Discharge Planning Coordinators of Ontario, 2009)

e) Integrated Case Management

- “Integrated case management is a team approach used to create and implement a service plan for clients. In this approach, each person is an equal member of the team. The team works together to identify an integrated case manager, who may be the client or one of the service providers, and to develop, implement, review and evaluate an integrated service plan”.


- “Integrated case management refers to a team approach taken to co-ordinate various services for a specific child and/or families through a cohesive and sensible plan. All members of the teamwork together to provide assessment, planning, monitoring and evaluation. The team should include all service providers who have a role in implementing the plan, and whenever possible, the child or youth's family”.


- “Integrated Case Management (ICM) is a concept that brings together inputs, delivery, management and organization of services related to diagnosis, treatment, care, rehabilitation and health promotion. This definition emphasizes the merging of all the elements related to care in a unified service.
- Integrated case management is an essential component of integrated care, which aims to improve services for vulnerable patients at highest risk of clinical complications.
- Case management is a service, led by a case manager (or a case management team) that provides proactive, coordinated care to people who have an intricate mix of health and social care needs. It provides an intense level of care, preventing people from unnecessary admission to hospital and providing more care in the person’s home or community setting.
- To the user, integration means a process of care that is seamless, smooth and easy to
navigate.
• **To the frontline provider**, it is working with professionals from different fields and coordinating activities and services across traditional professional boundaries.
• **To the manager**, integrated care means merging or coordinating organizational targets and performance measures, and directing and managing larger and more diverse professional teams;
• **To the policymaker**, integration means merging budgets, and undertaking program evaluations, which recognize interdependency of different providers and thus require assessments of broader care packages. The most important trade-off is between user and provider perspectives; effective models of care need to focus on integration at both levels. *(Lloyd J and Wait S. Integrated Care: a guide for policy-makers, Alliance for Health Europe, 2006).*

f) Caregiver assessment

• “A systematic process of gathering information that describes a care giving situation and identifies the particular problems, needs, resources and strengths of the family caregiver. It approaches issues from the caregiver’s perspective and culture, focuses on what assistance the caregiver may need and the outcomes the family member wants for support, and seeks to maintain the caregiver’s own health and well-being. *(National Center on Caregiving at Family Caregiver Alliance, “Caregivers Count Too! A Toolkit to Help Practitioners Assess the Needs of Family Caregivers, June 2006)*.

• “(1) Assessment is a systematic process, not a quick judgment; (2) the caregiver, not the patient, is the focus; and (3) the process recognizes the caregiver’s needs and vulnerabilities as well as strengths.
• For family caregivers, an assessment is a chance to talk about their own lives for perhaps the first time in any encounter with the patient’s health care team. They can express concerns about their own abilities to provide certain kinds of care, and the realities of their own situations. In health care settings, assessments will necessarily be brief but they can raise questions that the family caregiver can discuss further with others and can suggest types of resources that may be available and helpful.
• Some professionals are reluctant to ask questions about the kinds of help that a caregiver may need, because they cannot fill those gaps. But most caregivers are grateful for any suggestions and for the attention being paid to them. *(Assessing Family Caregivers, United Hospital Fund, 2008)*

g) Wraparound Services

• Wraparound is a planning process that is designed to create an individualized plan to meet the needs of children and their families by utilizing their strengths. Wraparound is an established vehicle for delivery of services and supports to children and families with severe and multiple needs and risks being served by multiple agencies.
• Wraparound refers to an individually designed set of services and supports provided to children with serious emotional disturbance or serious mental illness and their families that includes treatment services, personal support services or any other supports necessary to maintain the child in the family home.

• Wraparound services are to be developed through a team approach that includes the child/youth, parent(s) or guardians, other services providers/agencies, schools, extended family and friends and others that the child and/or family identifies that work together toward a common mission.

• Wraparound services are a particularly effective approach in serving children served by multiple systems.

(Michigan Department of Community Health Website, 2010)
Appendix IV: A MODEL BUILDING STRATEGY FRAMEWORK

Model Building as Change Strategy
This Project needs to be strategic to build momentum for change in a highly complex and challenging environment. In order to be sustainable and continue to strengthen and evolve over time, the model and model demonstration project need to be seen in a longer term and broader context of leading change. ("Leading Change", John Kotter, Harvard Business School Press, 1996). There are eight strategic phases of leading change that are all relevant to this Project:

1] Establish a Sense of Urgency
2] Form a Powerful Guiding Coalition
3] Create a Vision
4] Communicate that Vision
5] Empower Others to Act on the Vision
6] Plan for and Create Short-Term Wins
7] Consolidate Improvements and Keep the Momentum for Change Moving
8] Institutionalize the New Approaches

1] Establish a Sense of Urgency
Currently, there is no collected or readily available data on Aboriginal children with complex health needs or the issues they have experienced or re-admissions data to serve as a baseline for this project or to suggest the level of risk or urgency of the Project. VIHA has, however, established a priority for making its services accessible to rural and isolated Aboriginal people and has established Nurse Liaison positions across the Island based in hospitals in response to many of the issues identified here. A sense of urgency is necessary in direct proportion to the amount of new resources that will be requested for the model and model demonstration project. Case examples from these nurses and other data (including new baseline data collection as necessary) can help to fill the gap as required to establish urgency for action.

2] Form a Powerful Guiding Coalition
This project has a broadly representative Steering Committee of subject matter experts and key participants in the BC and Vancouver Island health system. Additional leadership support as needed to champion and inform the Project should be engaged and kept engaged to ensure that the direction proposed is supported in a time of conflicting priorities and constraint. In addition the Guiding Coalition can help to:
- Determine what is collectively known about discharge practices that work well
- Determine collectively know about the children and families to be served by the Project
- Collectively help to design the essential Project framework

3] Create a Compelling Vision
A vision is a compelling statement of direction in which an organization or enterprise/system needs to move (It is the anchor point for a change strategy). This Project’s success rests on a picture of the future that is relatively easy to communicate and appeals to stakeholders. A
A compelling long-range vision for this project needs to be developed and the model demonstration project located as a step towards realizing that vision. The shared vision builds unity of purpose and guides project work. A presentation outline of the model can serve as the vision communication document. Much of that work has been done. The opportunity for change exists and the Project is timely and needed. The framework for creating a compelling Vision document is:

- A Vision Statement
- Guiding Principles for the Model
- Five or so Key Result Areas of the Model (where excellence is required)
- Three-five Key Result Statements within each area identifying the objectives to be accomplished
- Definition of the work required in project management terms to overcome identified issues that impede the achievement of the Vision and Key Results

4) Communicate that Vision
This Project requires specific stakeholders to understand, appreciate, support and commit to the Vision. A stakeholder engagement and communication plan for the Vision is required to accomplish that, enable the communicators and stakeholders and keep all communication consistent.

5) Empower Others to Act on the Vision
The operating principle is to use every existing communication channel and opportunity to present and discuss the vision as part of the process for gaining input into the model design and subsequent participation from those interested in the model demonstration project. The model needs to be as “scalable” (able to expand or replicate) as possible to include people who want to participate.

6) Plan for and Create Short-Term Wins
Identifying Project scope including the model demonstration project team will help keep the urgency level up and will clarify or revise what short term wins are feasible-and sustainable over time.

7) Consolidate Improvements and Keep the Momentum for Change Moving
A model demonstration project should directly lead to the model becoming an identifiable “Program” or the new way things are done for Aboriginal children with complex health needs and their families-and others. It should be seen as the “initiation step” in a continuing process of evaluation and improvement. Without this sense of momentum a model demonstration project can actually impede progress and become one of many interesting but isolated “points of light” that has limited impact.

8) Institutionalize the New Approaches
The more people who have been involved in the Project and feel ownership of its successes the more they will support it moving forward and the more relevant, important and sustainable it will be.
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