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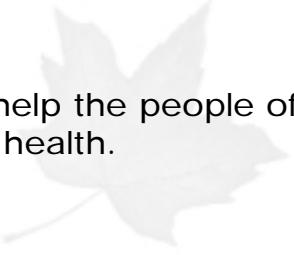
# The Health Transition Fund



SYNTHESIS SERIES

Children's Health

Canada



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**The Health  
Transition Fund**



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**Children's Health**

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This report is one in a series of 10 syntheses of HTF project results covering the following topics: home care, pharmaceutical issues, primary health care, integrated service delivery, Aboriginal health, seniors' health, rural health/telehealth, mental health, and children's health. The tenth document is an overall analysis. All are available electronically on the HTF website ([www.hc-sc.gc.ca/htf-fass](http://www.hc-sc.gc.ca/htf-fass)), which also contains information on individual HTF projects.

## Executive Summary

**T**he Health Transition Fund (HTF), a joint effort between federal, provincial and territorial governments, was created out of the 1997 federal budget to encourage and support evidence-based decision making in health care reform. Between 1997 and 2001, the HTF funded 141 different pilot projects and/or evaluation studies across Canada. In order to communicate research evidence from these projects to decision-makers, experts were employed to synthesize the key process and outcome learnings in each of nine theme or focus areas: home care, pharmaceutical issues, primary care/primary health care, integrated service delivery, children's health, aboriginal health, seniors' health, rural/telehealth and mental health. This document summarizes the key learnings in the children's health theme area. It has been prepared by Dr. Claude Roy, Professor Emeritus at the University of Montréal and staff member of the Department of Pediatrics at l'Hôpital Sainte-Justine and Ms. Karen Kidder, Director of Research at the Canadian Institute of Child Health.

### Children's Health in Canada

Of the 141 projects that were funded by the HTF, 28 tested and evaluated diverse ways to deliver a wide range of services to promote the "global health" of children and youth in Canada. This document presents the results of a thorough analysis of these reports and focuses on linking research to policy and practice. For the purposes of analysis, the 28 reports were divided into four categories, namely: pregnancy, birthing, and neonatology; child development; mental health; and integrated health services.

The five reports relating to pregnancy, birthing, and neonatology highlight the importance of enriching services for all mothers and infants as well as enhancing targeted programs. They establish the importance of

quality human resources, especially in the delivery of specialized care. The reports describe the importance of strengthening the quality of communication through networking, participatory case management, and information sharing, and they demonstrate the need for strong relationships between all health care providers involved with a mother and her infant. Analysis of these reports collectively reveals the potential advantages for parents of "one-stop shopping," where programs offer services that meet a broad spectrum of needs. This approach implies important structural changes, which will only come about by involving all stakeholders and appropriately funding the community sector as it delivers these services.

Detailed analysis of the nine reports dealing with child and youth development indicates that the single most important goal of these community programs is to make sure that no child is "left behind" and that all families have access to the supports they need in order to meet the developmental needs of their children. A proven strategy, supported by the HTF reports, to secure access, quality of care, and cost-effectiveness is the enhancement and integration of services, as opposed to the multiplication of services. Strong leadership by a dedicated coordinator; involvement of all stakeholders, including youth; and an anticipatory approach contribute to the success of community programs. Partnerships between professionals and community organizations involved in health care, social services, and education are important, as the sustainability of programs often depends on the quality of partnerships. While there is a recognized need to foster optimal development and build resilience in children by providing interventions during infancy and the preschool years, such programs should not be introduced at the expense of programs for school-aged children and youth.

There is no area of child and youth health and well-being where a family-centred and community-based approach is more important than in mental health. Thus, it was encouraging to note that many HTF projects emphasized empowering families and communities for both prevention and treatment; “going where the children are” (e.g., child care centres and schools) to provide services; and implementing this approach on a much broader scale. According to the six HTF reports on the mental health of children and youth, linking professional and community organizations as well as self-help parent groups to ensure the exchange and dissemination of reliable information contributes to the empowerment of parents. Similarly, family liaison activities can improve access to services, facilitate compliance, and greatly enhance the efficacy of interventions. The HTF reports indicate that the integration of services and the use of specialists can lead to reduced use of out-of-province resources, improved access, and enhanced quality of care. It is important to improve access to integrated, family-focused mental health services and a range of delivery options and to improve the early screening of children with mental health needs. Professional education is necessary to teach not only health care workers, but also child care providers and teachers how to recognize and respond to mental health needs. The principles of networking, partnering, parental involvement, and specialized training common to many of the HTF projects are transferable, but the structures are likely to be different, since they must be adapted to local conditions.

Although the early stages of health reform were largely driven by short-term cost-effectiveness, the eight reports that examined integrated services addressed overarching issues such as decentralization and coordination of services, professional development and retraining of the workforce, and delivery

of services in non-clinical settings. The HTF reports demonstrate that building networks across sectors is an important component of health reform and must be accompanied by close involvement of all stakeholders. They attest to the importance of having mechanisms in place to ensure that even the smallest partner has a voice. The proliferation of community organizations is a clear signal that people want to have a share in making decisions about their health and well-being and that the community sector is a vibrant and essential partner. Unfortunately, their efforts are often fragmented and uncoordinated. The HTF reports illustrate the need for government support to the community sector and improved collaboration across sectors. Government funding of pilot programs is important, but so is stable funding for community organizations and for established, effective programs.

A number of themes threaded throughout many of the HTF reports, suggesting that such things as high-quality training and ongoing professional development; high-quality communication between all service providers; the overall integration of health and social services; and effective, appropriate approaches to service delivery (including in some cases delivery of services in non-clinical settings, such as day cares and schools) are important to the success of a wide range of ventures.

Overall, the findings from the HTF reports support the position that health policy decisions concerning Canada’s children and youth need to be based on evidence generated by research, but powered by a greater community and user involvement in health care and child advocacy. They attest to the importance of developing strategies adapted to local environments and to involving parents and community organizations in the process.

## Preface

**I**n recent years, Canada's health care system has been closely scrutinized with a view to quality improvement and cost-effectiveness. Fiscal pressures and changing demographics are resulting in initiatives to explore how the efficiency of the health care system can be increased while ensuring that high-quality services are affordable and accessible. Within this context, there has been a need for more research-based evidence about which approaches and models of health care have been working and which have not. In response to this requirement for evidence, and on the recommendation of the National Forum on Health, the Health Transition Fund (HTF) was created out of the 1997 federal budget to encourage and support evidence-based decision making in health care reform.

A joint effort between federal, provincial and territorial governments, the HTF funded 141 pilot projects and/or evaluation studies across Canada between 1997 and 2001, for a total cost of \$150 million. Of that, \$120 million supported provincial and territorial projects and the remaining \$30 million funded national-level initiatives. The HTF targeted initiatives in four priority areas: home care, pharmaceutical issues, primary health care, and integrated service delivery. Various other focus areas emerged under the umbrella of the original four themes, including Aboriginal health, rural health/telehealth, seniors' health, mental health, and children's health.

The HTF projects were completed by the spring of 2001. In order to communicate the evidence generated by the projects to decision-makers, experts were employed to synthesize the key process and outcome learnings in each theme area. This document summarizes the key learnings in the children's health theme area. It has been prepared by Dr. Claude Roy, Emeritus Professor and staff member, Department

of Paediatrics, L'Hôpital Sainte Justine; and Ms. Karen Kidder, Director of Research, the Canadian Institute of Child Health.

### Unique Nature of the HTF Projects

The HTF was quite different from other organizations that fund health-related research in this country, such as the Canadian Institutes for Health Research and its predecessor the Medical Research Council.

- It was a time-limited fund, which meant that projects had to be conceived, funded, implemented, and evaluated all in four years – a very short time in the context of system reform.
- It was policy-driven; policy-makers were involved in the project selection process, and wanted to focus on some of the outstanding issues in the four theme areas in the hope that results would provide evidence or guidance about future policy and program directions.

In order to encourage projects to address issues and produce results that would be relevant to decision-makers, the HTF developed an evaluation framework consisting of six elements (access, quality, integration, health outcomes, cost-effectiveness, and transferability). Each project was required to have an evaluation plan addressing as many of these elements as were relevant. In addition, all HTF projects were required to include a dissemination plan (for which funding was provided) in order to ensure that results were effectively communicated to those best able to make use of them. In addition to these individual dissemination plans, the HTF Secretariat is implementing a national dissemination strategy, of which these synthesis documents are one element. This emphasis on evaluation (systematic learning from the experience of the pilot initiatives) and dissemination (active sharing of results) was unique on this scale.

Most national projects were selected by an inter-governmental committee following an open call for proposals, while provincial/territorial initiatives were brought forward by each individual jurisdiction for bilateral approval with the federal government. At both levels, applications came not just from academics in universities, or researchers in hospital settings, but also from non-traditional groups such as Aboriginal organizations, community groups, and isolated health regions. Groups that had rarely, if ever, thought in terms of research, evidence, evaluation, and dissemination began doing so, and these developments bode well for improved understanding and collaboration among governments, provider organizations, and researchers. The role of federal, provincial, and territorial governments in the selection process ensured that the projects delved into the issues that were of high concern in each jurisdiction. By the same token, there was considerable scope in the range of project topics, and the body of projects was not (and was never intended to be) a definitive examination of each theme.

This unique focus and selection process imparts specific features to the HTF body of projects. The projects that were funded represent good ideas that were put forward; they do not represent a comprehensive picture of all the issues and potential solutions in each of the theme areas. The relatively short time frame meant that many researchers struggled to complete their work on time and the results are preliminary or incomplete; some pilot projects might take a number of years to truly show whether they made a difference. This must be left to others to carry forward and further investigate. Perhaps the greatest value in the large body of HTF projects comes from the lessons we can learn about change management from the researchers' struggles and challenges as they undertook to implement and evaluate new approaches to longstanding health care issues.

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# 1. Setting the Context

## 1.1 Overview of This Project

This document is based on an analysis of 28 individual projects (see Appendix A) addressing a broad range of problems and issues that affect the development, the physical/mental health, and the social integration of children. Four one-day meetings (May 8, 14, 25, and July 23, 2001) were held in Ottawa to review the reports and facilitate presentation of the findings, recommendations, and policy implications. The 28 reports were grouped under four theme categories:

- pregnancy, birthing, and neonatology;
- child development;
- mental health; and
- integrated health services

The evidence generated by these reports, reinforced by collective beliefs and social concern, form the foundation for this synthesis report. It calls for the development of a national vision for child and youth health and the strategies required to make it a reality.

## 1.2 National Children's Agenda

The National Children's Alliance, founded in 1996, is a group of more than 30 national organizations committed to the well-being of all children and youth in Canada. In 1997, the lobbying of the Alliance, its member organizations, and other groups resulted in a federal government commitment to develop a comprehensive strategy to improve the lives of Canada's children. The Alliance and other child-, youth-, and family-focused organizations were pleased to note that Health Minister Allan Rock launched this National Children's Agenda (NCA) by stating, "Children are our future. Moving forward together on a National Children's Agenda will allow us to ensure that our kids will have the best possible start in life. This

initiative confirms that the health, quality of life, and future of Canada's children is a shared priority for all jurisdictions." The evidence gathered in this HTF synthesis report contributes to the NCA goals, offering insights into how best to ensure that Canada's children and youth are:

- healthy, physically and emotionally;
- safe and secure;
- successful at learning; and
- socially engaged and responsible.

Using traditional physical health indicators of infant and child mortality, communicable diseases, and hospitalization data, it can be concluded that Canadians have made substantial gains in improving the health of children and youth. However, renewed energies and strategies are needed to address new indicators that describe the development and health of children where they are: in families, schools, and communities. Ongoing and emergent issues that strongly require attention are discussed in the following sections.

## 1.3 Pregnancy, Birthing, and Neonatology

A child's health is inseparable from that of his or her mother and the family. Throughout the period before conception, the pregnancy, and infancy, the mother's biology as well as her social and physical environments are key determinants of the health of her offspring. Maternal, child, and family health constitute a complex web of mutually interdependent biological and social contingencies. All of these contingencies must be taken into account to positively influence reproductive and developmental outcomes. The major issues in this area are:

- the shift in maternal age at the two ends of the age spectrum (teenage pregnancies and a higher proportion of live births after the age of 35 years);
- substance abuse during pregnancy;

- fetal alcohol syndrome and effects (FAS/E);
- poor nutrition during pregnancy due to poverty;
- physical abuse during pregnancy;
- preterm and multiple births;
- congenital anomalies;
- early discharge from hospital after birth;
- home births;
- the initiation and duration of breastfeeding; and
- Sudden Infant Death Syndrome (SIDS).

An overview of Canadian statistics on pregnancy, birthing and the neonatal period can be found in *The Health of Canada's Children: A Canadian Institute of Child Health Profile* (Kidder, et al., 2000).

## 1.4 Child and Youth Development

There is powerful new evidence in recent research that the early years of development from conception to age six, but particularly the first three years, set the stage for competence and coping skills that will affect learning, behaviour, and health throughout life (McCain & Mustard, 1999). It is essential that supports be in place to help parents meet the developmental needs of their young children. Youth also have age-specific needs and require appropriate services and supports that they can access themselves. The major problem areas regarding child and youth development are:

- childhood poverty, affecting parenting, housing, nutrition, education, and risk behaviours;
- insufficient targeted services adapted to the needs of poor and at-risk children;
- the accessibility and quality of family support programs, regulated child care facilities, and out-of-home services;
- safe environments, safety equipment, safe behaviours, and the prevention of injury;
- exercise and nutrition;
- accessible community recreation programs;
- monitoring and improving the “school readiness” of young children;
- children at home alone;
- sexual and reproductive health of youth;
- healthy connections between children and youth, their peers, parents, and teachers; and
- the inclusion of all children, at home, at school, and at play, regardless of disability status, income, or other potentially challenging factors.

## 1.5 Mental Health

Canadian children enjoy one of the highest standards of living and have among the best health outcomes of children worldwide. Yet the epidemiological literature shows that about 20 per cent of Canadian children and adolescents present neuropsychiatric and/or behavioural symptoms (Offord et al., 1999). There are a number of determinants of mental health that significantly increase that risk (Cassidy & Jellinek, 1998). These determinants are biological, cultural, economic, and social. While some children and youth are at greater risk, such as children living in poverty, mental health and behavioural problems are found in all socio-economic groups and are appropriately termed the “new morbidity” for children and youth (Kidder, et al., 2000). The major areas of concern regarding child and youth mental health are:

- aggression and bullying;
- child abuse and neglect;
- children witnessing violence;
- children receiving services from the child welfare system;
- resilience;
- services to support parents;
- children and youth connectedness with family and school;
- hyperactivity, conduct disorder, and emotional problems;
- anxiety and depression;
- suicide; and
- the need for accessible, high-quality mental health services for children and youth.

## 1.6 Integrated Health Care Services

The current trend in health care delivery is to implement integrated delivery systems (CIHI, 2001). Through regionalization and the creation of health care networks, there are now better links between primary care and secondary/tertiary levels of care. Primary health care is expected to be accessible, continuous, comprehensive, coordinated, and closely connected with community social services, the child care and school system, as well as with a plethora of agencies responsive to the health needs of children and youth. Health reform is the result of the recognition that health care services are not nearly as important as social, economic, and environmental factors in producing health and well-being. Coping with this fundamental change in our society's approach to health and illness has led to major structural changes in our health care system. However, several problems remain and should be noted:

- undue fragmentation of child health services and uneven quality of care;
- hasty regionalization of care in areas such as neonatology, oncology, and children's mental health in the absence of adequate numbers of appropriately trained health care providers;
- lack of accessible, high-quality mental health services for children and youth;
- the dismantling of school health programs, which constitute an ideal non-clinical setting for school age children and adolescents; and
- the devolving of child health care to inexperienced first-line physicians, decreasing the capacity for anticipatory guidance.

## 2. Overview of the HTF Studies

**A**s noted above, the 28 HTF reports reviewed seemed to cluster into four major areas: pregnancy, birthing, and neonatology; child development; mental health; and integrated health services.

Table 1 lists the specific reports to which this paper refers, by category. Short summaries of these reports can be found in Appendix A.

In view of the broad range of themes and approaches, it is difficult to provide an overview of these reports. However, the five studies on pregnancy, birthing, and neonatology, the nine on child development, the six on mental health, and the eight dealing with integrated health services are focused both on children in their initial stages of development and on the family and school environment critical for health, well-being, and integration into society. The child is at centre stage and the research efforts are targeted to national health priorities and public health needs. There is good integration across disciplines and a remarkable degree of inter-sectoral (university, government, community) collaboration as well as partnerships with all stakeholders.

As noted in the Preface, the HTF was a unique initiative that provided funding to both develop and evaluate new initiatives. Thus, the majority of studies were smaller demonstration and pilot projects or evaluative research studies on intervention strategies already in place. Both quantitative and qualitative research approaches were used. Given these realities, there was a range in the methodological quality of the evaluations that were conducted. Some were hypothesis-driven and well controlled, while others were more descriptive in nature.

It was heartening to see that the conceptualization and conduct of the research involved health care workers and educators in the field and often research subjects. Researchers worked explicitly with and for children, their families, and others, such as child care providers and teachers. The strength of this approach was that it has the potential –

- to bridge the gap between research findings and practice;
- to generate solutions to practical problems; and

- to to empower field workers and the target population.

However, the community-centred research often did not have the robustness needed to fully attain these goals, and it was sometimes handicapped by the shortness of the funding period.

**Table 1: HTF Reports by Category**

CATEGORY	REPORTS
<b>Pregnancy, Birthing and Neonatology</b>	SK323: <i>“Born Healthy, Raised Healthy” – A Breastfeeding and Nutrition Support Program</i> (\$191,733) PE321: <i>Enhancement of an Integrated Model of Prenatal Assessment and Care on PEI</i> (\$100,000) BC404: <i>Home Birth Demonstration Project</i> (\$167,400) BC422: <i>Integrated Postpartum Care and Lactation Support</i> (\$63,037) NA1017: <i>Neonatal Transitional Care Program Evaluation</i> (\$65,385)
<b>Child Development</b>	NB301: <i>Analysis of School Readiness Data</i> (\$25,000) SK329: <i>Day Care Consultation Services</i> (\$140,000) AB301-14: <i>Healthy Families Primary Health Care Service to High Risk Families</i> (\$805,917) AB301-21: <i>Healthy Families Project</i> (\$481,642) SK328: <i>Lloydminster’s “First Steps” Program</i> (\$153,096) SK332: <i>Parenting Plus: Early Childhood Development Program</i> (\$186,991) PE422: <i>Provincial Social Support Program for Teen Parents</i> (\$137,500) SK322: <i>Roots and Wings: Prevention of Child Abuse/Neglect</i> (\$280,246) NS401: <i>Sharing Strengths: A Child and Youth Health Strategy</i> (\$458,600)
<b>Children’s Mental Health</b>	PE421: <i>Autism Integration Project</i> (\$171,831) QC424: <i>Development and Evaluation of a Cultural Mental Health Consultation Service</i> (\$449,676) BC403: <i>Eating Disorders Project North (EDPN)</i> (\$277,870.48) AB301-9: <i>Enhance and Evaluate COPE (Community Outreach in Pediatrics/Psychiatry and Education)</i> (\$494,800) SK324: <i>Evaluation of Integrated Services for Families of Aggressive School-Aged Children</i> (\$171,600) SK423: <i>Integrating Services for Families with Affective Disorder: Implementing and Evaluating a Preventive Program in Saskatchewan</i> (\$127,750)
<b>Integrated Health Services</b>	SK334: <i>Developmental Program Evaluation: Planned Parenthood Regina Sexual Health Centre – “Getting it Together”</i> (\$166,665) NA132: <i>Home Chemotherapy for Children with Cancer: An Evaluation of Costs and Health Services Utilization</i> (\$63,105) QC411: <i>Integrated Delivery of Youth Services in Quebec</i> (\$1,684,965) SK331: <i>Monitoring the Effects of Family Health Benefits for Low Income Families in Saskatchewan</i> (\$113,345) QC305: <i>Supra-Regional Mother-Child Network</i> (\$2,278,514) NA161: <i>Tele-Home-Care: Multi-Site Modeling Component</i> (\$87,240) QC410: <i>Transformation of Community Organizations’ Practices in Connection with the Reorganization of the Health and Social Services Network</i> (\$253,946) AB301-20: <i>What are the Client Characteristics and Their Perceived Barriers for Non-adherence to Immunization Schedules and What Impact Will an Immunization Refusal Strategy have on Subsequent Adherence at Six Months, 12 Months and 18 Months?</i> (\$115,804)

## 3. Discussion of Significant/ Relevant Findings

### 3.1 Pregnancy, Birthing, and Neonatology

**T**he majority of infants in Canada are born healthy and continue to thrive during childhood. However, there are regional discrepancies in the capacity of health care systems to identify high-risk families early and make prompt referrals to appropriate services. The unchanged rate of low-birth-weight infants and the dramatically increased rate of multiple births contribute substantially to perinatal morbidity and mortality. Further, although the benefits of breastfeeding have been made clear, the prevalence and duration rates of breastfeeding have not responded to public health messages. Finding strategies to deal with these issues should be a priority.

#### 3.1.1 Lessons Most Relevant to Policy and Practice

Standards of care should not be changed until compelling evidence is presented that these changes lead to improved outcomes rather than deterioration. In this regard, the *Home Birth Demonstration Project* (BC404) is of concern in that the risk of worsened outcomes (such as obstetrical shock) may prove to outweigh the benefits (such as fewer interventions) as more data is collected. Although it may be premature to change standards of care, the evidence presented by BC404 establishes that continuing demonstration projects in this area are important to gather additional information and to refine protocols.

The accessibility of community programs targeted to high-risk mothers and infants, and the quality of care delivered, are strongly influenced by the quality of the human resources. In this regard, specialized training, with an emphasis on field training and theoretical

training, preferably in post-secondary settings such as community colleges or universities, is key to success. This level of training must then be maintained after the pilot period. Insufficient attention to the education and training of health care and community workers may jeopardize the long-term success of conceptually valid initiatives. The importance of this issue is highlighted in *The Neonatal Transition Care Program Evaluation* (NA1017) and, to some extent, in BC404.

There is a clear responsibility to match funding and human resources with the level of need, focusing attention on programs that serve high-risk or special need populations. For example, NA1017 validates the need for a different level of support for the parents of low-birth-weight and very-low-birth-weight infants. The findings from this project indicate that when the level of support for parents is appropriate, outcomes can be improved. In this case, for example, babies were more often breastfed and there was better compliance to medication regimens.

Outreach and the offer of immediate services and products, such as food supplements and clothes, are extremely important aspects of programs targeted to vulnerable populations of women and infants. They increase the likelihood that women will enroll and participate in other kinds of services such as individual counseling and group sessions. "*Born Healthy, Raised Healthy*" – A Breastfeeding and Nutrition Support Program (SK323), which represented an enhancement for a very vulnerable population, depended heavily on outreach, a reality that should be recognized in the funding process. Expectant, high-risk mothers were contacted as early as possible in their pregnancy through a storefront and outreach program.

SK323 also showed the importance and relevance of interventions to ensure that low-income pregnant women receive corrective nutritional allowances (consistent with the Canada Prenatal Nutrition Program model). This program provided information, coordinated access to health care services, and breastfeeding support. Mothers were assisted in developing community resources, such as community kitchens and peer support groups. The interventions appeared to have an immediate impact at the level of the individual. This program demonstrates the potential of community-based programs delivered in neutral, non-judgmental ways (through, for example, a focus on nutrition), and the importance of outreach and case management.

Health reform has largely been directed toward containing the costs of the health care system. Admittedly, the cost-effectiveness of programs is important in the health care system's equation. More importantly, health reform has led to significant improvements in encouraging individuals to assume responsibility for their own health care and in providing consumers with choices, with emphasis on ambulatory care, home care, and community care. The five projects concerning pregnancy, birthing, and neonatology do not provide us with data on the cost-effectiveness of such programs. However, all of them could represent substantial savings in view of their orientation to preventing adverse health outcomes. This applies particularly to early identification of families at risk during pregnancy (PE321 and SK323) and to the provision of intensive support to the families of low-birth-weight babies (NA1017).

The project *Enhancement of an Integrated Model of Prenatal Assessment* (PE321) demonstrates the feasibility of psychosocial screening by physicians during prenatal assessment and care. This screening has significant potential to improve maternal and infant outcomes through early identification and intervention. However, while validated instruments

for universal screening can increase the cost-effectiveness of services by facilitating the identification of mothers and infants most at risk, they may miss, because of their necessarily limited focus, some mothers and infants who would potentially benefit from social and health programs. This is one of the reasons that it is advisable to enhance universal programs as well as targeted ones and to ensure that self-referral is easy and straightforward.

### 3.1.2 Broadly Applicable Lessons

Five broadly applicable lessons were developed based on these five reports. The implications of our findings were that policy-makers should consider the following issues:

- Services for all mothers need to be enriched. Problems arise in all groups and are not restricted to the high-risk populations.
- Integration and coordination of services must be enhanced and improved, with services targeted to special needs groups.
- We must ensure the quality of human resources, their appropriate deployment, and access to the appropriate level of care.
- It is important to strengthen the quality of communication (for example, through networking, shared case management, or information sharing). Strong relationships are needed between all health care providers involved with a mother and infant.
- Appropriate training for health care personnel must be secured.
- The full spectrum of services thought to influence outcomes should be made accessible in a “one-stop shopping” mode at the local level by qualified personnel. This will ensure increased access and promote quality of care. This implies important structural change, which will only come about by involving all stakeholders and appropriately funding the community sector as it delivers these services.



## 3.2 Child and Youth Development

It is clear that the social environments of children have considerable impact on their physical, psychological, cognitive, and behavioural development. There is serious concern that too many children spend time in environments that do not foster optimal development. These children may be challenged by abuse, neglect, social isolation, poverty, and/or a lack of positive stimulation and affection.

### 3.2.1 Lessons Most Relevant to Policy and Practice

Although experimental research leading to results that can be meaningfully assessed is vitally needed, it can be decidedly difficult to accomplish when the families involved have major needs that must be met or psychosocial problems that inhibit them from participating. Services for these families cannot wait upon quantitative, experimental research. Projects such as *Healthy Families Primary Health Care Service to High Risk Families* (AB301-14), *Healthy Families Project* (AB301-21) and *Roots and Wings: Prevention of Child Abuse/Neglect* (SK322) demonstrate that intensive projects like these can make an immediate difference, at least at the level of the individual.

It is evident that meeting the needs of families requires community effort and cannot be addressed by any single organization. Increased collaboration is needed, especially for hard-to-serve families. Effective collaboration requires quality communication among partners and stakeholder involvement from the planning stage. On the one hand, this is well demonstrated from a broad, community-planning perspective in *Sharing Strengths: A Child and Youth Health Strategy* (NS401). On the other hand, SK322 illustrates the problems that emerge even in well-designed research projects when quality communication is not established in the planning stage.

Positive social environments, as well as access to medical care, shape health. It is, thus, important to empower families to take responsibility for their child's developmental needs. Programs such as *Lloydminster's "First Steps" Program* (SK328) aim to accomplish this goal in a non-judgmental, community-based way. Aimed at improving parents' abilities to meet their children's developmental needs, SK328 proved useful in linking fragmented community services and, in so doing, improving access to, and the quality of, services. The need for support can change swiftly in families with infants and young children. Consequently, programs, ensuring multiple points of access, easy referral and self-referral, and a variety of program options serve an important function.

Partnerships and/or collaborations between community agencies and professional organizations (such as collaboration between child care providers and health and social services organizations) are one option for improving access to services. The effectiveness of this approach is demonstrated in *Day Care Consultation Services* (SK329), a project that brought high-quality mental health consultation services into the day-care setting. The child care providers were responsible for implementing the intervention plan. This professional development had a global and targeted impact because although the interventions were designed for specific children with behavioural problems, the skills learned regarding intervention were applied to all children. Locating services in the day-care setting can improve access to services (the services are delivered where the children are and, in some cases, where the problem behaviour is manifesting itself) and may also improve the odds of involving high-risk families who might otherwise not access or agree to services.

In considering the lessons learned from SK329, it is important to remember that "scaled up" programs (moving from the local level to the regional or provincial level) need to incorporate quality of care

assessments both before and after services become part of the standard of care. Services should not become part of the standard of care until quality of care is assured, positive outcomes are demonstrated, and specialized training requirements are set. This caution echoes and underlines the lessons learned from the *Home Birth Demonstration Project* (BC404) and the *Neonatal Transitional Care Program* (NA1017), which were reported upon in Section 3.1.1.

In *Parenting Plus* (SK332), researchers learned the hard way that in order to promote collective ownership of a program, it is essential to involve all stakeholders in the planning process and ensure that they have a voice. This program, aimed at improving parenting skills and reducing the incidence of child abuse, experienced difficulties meeting its objectives because strong relationships had not been established with key stakeholders (such as First Nations communities and hospitals) prior to implementation. High-quality communication and commitment on the part of all stakeholders are essential if programs of these kinds are to succeed.

### 3.2.2 Broadly Applicable Lessons

Five broadly applicable lessons were derived from these nine reports relating to child development.

- There is a need to foster optimal development and build resilience in children by providing interventions during infancy and the preschool years. However, such programs should not be introduced at the expense of programs for school-aged children and youth.
- To better ensure access, quality of care, and cost-effectiveness, governments should support the enhancement and integration of services, rather than the multiplication of services.
- Doing the groundwork prior to initiating a project is key to success. Strong leadership by a dedicated coordinator; involvement of all stakeholders, including youth; and an anticipatory approach and perspective contribute to success.

- Partnerships between health care, social service, and education professionals and community organizations should be fostered and supported. A program's sustainability is often determined by the quality of the partnerships.
- Universal screening with a psychosocial component should be ensured, and follow-up services should be comprehensive and continuous, from the prenatal period through birth and during infancy.

## 3.3 Mental Health

The child's environment remains an important mental health determinant, and modifying it remains a challenging responsibility if efforts to reduce the heavy burden of suffering from emotional and behavioural problems in children and youth are to succeed. There is undoubtedly a new mental health morbidity, reflected in the rates of childhood aggression, substance abuse, disordered eating patterns, and school drop-out. Although the advantages of providing mental health services in day cares and schools have been noted, this approach has yet to be implemented on an adequate scale. It is clear that effective, universal and targeted programs are needed to adequately respond to the mental health needs of children and youth.

### 3.3.1 Lessons Most Relevant to Policy Practice

Government funding for an additional year of preschool contributes to the healthy development of autistic children, helps smooth their transition into the school years, and is highly desirable, as indicated in the *Autism Integration Project* (PE421). There is also a need for policy directed at defining autism and its spectrum of manifestations, as well as its incidence which appears to be increasing.

PE421 also indicated that adequate remuneration of in-home workers is essential to ensure quality care for autistic children and their families. High turnover,

often a consequence of poor pay, is particularly disruptive for these children, so it is important to find ways to pay these workers an adequate salary. At the same time, we have to remember that in-home support is only one component of the range of services required by children with autism and their families.

PE421 succeeded, in part, because of the commitment and collaboration of both parents and professionals. This finding suggests that it would be a good policy to introduce standards of care for self-help groups and to require collaboration between self-help groups and professional organizations before providing government funding. Without this link, there is a danger that parents will ignore medical messages and start believing information that is not evidence-based.

As demonstrated in *Enhance and Evaluate COPE (Community Outreach in Pediatrics/Psychiatry and Education)* (AB301-9), family physicians can form an important part of a school-based team, facilitating access to primary health care and, through collaborative consultations with pediatricians, psychiatrists, and education specialists, building independent capacity to identify and treat children with unmet mental health needs. This lends support to the idea of “hub schools” that provide “one-stop shopping” for mental health, health, and social services. This approach views schools as a central part of their communities and not just vehicles of education.

Barriers to care, especially in mental health, confront minorities, refugees, immigrants, and Aboriginal persons. The evidence presented in *Development and Evaluation of a Cultural Mental Health Consultation Service* (QC424) suggests that culture-sensitive clinics are warranted to meet the specific needs of these populations and that they have proven their utility in large urban centres. Tailoring services to meet the specific needs of children and youth is an important consideration.

### 3.3.2 Broadly Applicable Lessons

Six broadly applicable policy findings were determined from the reports relating to the mental health and well-being of children and youth.

- Linking professional and community organizations as well as self-help parent groups is an effective means to ensure the dissemination of reliable information.
- Integrated services and the use of specialists can lead to the reduced use of out-of-province resources, improved access, and better quality of care as demonstrated in PE421.
- It is important to improve access to integrated, family-focused mental health services and a range of delivery options as well as to improve the early screening of children with depression. This will require education of health care workers, appropriate training and creation of multi-disciplinary teams.
- Parental empowerment and capacity building through family liaison activities will improve access to services, facilitate compliance, and greatly enhance the efficacy of initial interventions.
- Professional education to recognize and respond to mental health needs should be a priority not only for health care workers, but also for child care providers and teachers.
- The principles of networking, partnering, parental involvement, and specialized training are transferable, but the structures are likely to be different, adapted to local environments.

### 3.4 Integrated Health Services

A precondition for the success of health care reform is community-driven integration of health services. Right now a major concern is the existence of a fragmentary approach to services rather than a global, case management approach. The ability to provide integrated health services is challenged by understaffing and underfunding. Other problems arise when the skills of personnel and their responsibilities are not well matched.

### 3.4.1 Lessons Most Relevant to Policy and Practice

*Transformation of Community Organizations' Practices in Connection with the Reorganization of the Health and Social Services Network (QC410)* supports the position that the implementation of stable funding for the voluntary sector in all provinces would be a step towards ensuring the quality of staff in community organizations, optimal performance, and the sustainability of programs. Many community organizations providing services to children and families believe that stable funding constitutes fair compensation, without which, important programs can be compromised. It is clear, though, that in return the community organizations must be accountable to the public, through regular evaluation against multi-year performance indicators.

QC410 also provides evidence that the expertise and experiential knowledge of leaders in the voluntary sector should be recognized and appropriately remunerated. Their role needs to be redefined in the hope of achieving one-stop shopping and, thus, improved access to a broad spectrum of community needs (economic, social, cultural, and health). Community organizations need to partner with professional organizations and academic institutions to develop their knowledge and skills. However, community organizations are mission-driven, responding to the observed need in the community, and as such need to maintain autonomy.

Quebec's neighbourhood health centres (CLSCs) have been at the centre of the province's regionalization program and are mandated to provide a broad spectrum of health and social services. However, underfunding and poor staffing have undermined their credibility. As a result, the communities have responded by creating local services to meet observed needs. Unfortunately, the CLSCs and the community organizations have often found themselves in competition instead of in functional partnerships. This situation suggests that

the full value of the CLSCs and the community organizations are not currently being realized. *Integrated Delivery of Youth Services in Quebec (QC411)* validates many of the concerns that have been expressed by community organizations in Quebec and other provinces.

There are also concerns about telehealth, expressed by the report *Tele-Home-Care: A Multi-Site Modeling Component (NA161)*. There is currently little research on the actual benefits of this new technology in terms of child health and well-being, and currently this innovation appears driven by the information technologies sector. Although described in this report as complementary, among other services there is a fear that tele-home-care may lead to a decrease in traditional services. Policies are needed to ensure quality control and continuity of care. Governments need to act now to establish the standards of care for tele-home-care if they are to stay ahead of the technological innovation. To develop standards of care, governments will need to fund demonstration projects with well-constructed evaluation methodologies.

*Monitoring the Effects of Family Health Benefits for Low Income Families in Saskatchewan (SK331)* demonstrates that user charges are an obstacle to the purchase of prescription drugs. It demonstrates that making prescription drugs available free of charge to working poor families as well as to those on social assistance helps families overcome this obstacle.

### 3.4.2 Broadly Applicable Lessons

Six broadly applicable policy lessons were derived from the reports on integrated health care services.

- It is critical to assess what factors are driving a project and to recall that *short-term* cost-effectiveness should not be viewed as an adequate rationale. The major consideration should be the extent to which the project leads to the improved health and well-being of children and youth in the *long term*.

- Decentralization of care is theoretically desirable, but in practice, strict criteria must be established before moving secondary and tertiary care to the home and community primary care facilities.
- Building networks around academic health centres is an important component of health reform. However, there should be very close involvement of all stakeholders. Mechanisms should be in place to ensure that even the smallest partner has a voice; otherwise partners perceive networks as threatening and demeaning.
- Community organizations can benefit from close ties with academic health centres in order to build their capacity to conduct effective evaluative research. This is an important aspect of their accountability since, in doing so, they will contribute to the evidence base supporting health care reform.
- The proliferation of community organizations is a clear signal that people want their share of decision making in relation to their health and well-being, and that the community sector is a vibrant and essential partner. Unfortunately, their efforts are often fragmented and uncoordinated. Consequently, community organizations compete amongst themselves, with for-profit agencies, and with government agencies.
- Government funding of pilot programs is important, but stable funding for community organizations and established, effective programs is equally important as non-government funding sources generally do not fund recurrent programs or those of long duration.

## 4. Health Human Resources in Children's Health



According to *Health Care in Canada 2001* (CIHI, 2001), regionalization represents an effort on the part of provincial and territorial governments to engineer a health care system that would be “responsive and accountable to the people it served” (p.9). The goals of regionalization are to reduce duplication, increase cost-effectiveness, and ensure that optimal use is made of the health care system. For regionalization to succeed, the three tiers of health care services must be explained fully to communities and, in turn, relevant community services must be explained to health care centres so that everyone knows who does what, for whom, and can make appropriate referrals. Regionalization becomes a problem when it is interpreted as meaning that every region provides a full spectrum of required services.

The most effective use of health human resources can mean that services traditionally provided by doctors are delivered by others, such as specially trained nurses and midwives. This expertise needs to be created and maintained. For example, neonatal nurses who receive theoretical training at a university and practical training in a hospital are able to take sole responsibility for critically ill newborns. Success is conditional on the training, the positive relationship between nurses and physicians, and the commitment of hospitals to such programs. Changes in practice of this kind can be cost-effective ways to solve health human resources problems. This illustrates the desirability and feasibility of projects such as the *Neonatal Transitional Care Program* (NA1017) and other specialized community nursing programs.

Midwifery is, in part, a health human resource issue. As evidenced by the *Home Birth Demonstration Project* (BC404), to be an effective and safe alternative, midwives must be integrated within the health care system, including tertiary care facilities and emergency services. The quality of communication must be high, with all players understanding and complying with the referral and consultation process. When health providers have a clear mandate, appropriate training, and an effective and efficient referral process, their competence and confidence improve and the quality of care need not suffer.

The key issues in health human resources in the area of child development, as described in these HTF reports, relate to the breadth and accessibility of services for children and parents and the appropriate deployment of high-quality personnel. One approach to ensuring that all parents can meet their children's developmental needs is to make developmentally based, high-quality, regulated child care accessible, along with other community programs, such as *Lloydminster's "First Steps" Program* (SK328) or local versions of the *Healthy Families* model (AB301-14 and AB301-21).

Furthermore, field-training opportunities need to be made available to child care workers who are already employed in the sector. At present, child care workers are often generalists. Specialized training should be directed at those who are already delivering services to expand their capacity to meet the needs of infants, children, and, to some extent, parents. This strategy was well illustrated in *Day Care Consultation Services* (SK329). At the same time, restructuring in the child care sector must be predicated on adequate remuneration of child care workers. Without adequate remuneration, turnover rates will continue to be high and efforts to build a skilled and experienced staff will be undermined.

The importance of opportunities to learn skills in the field, and to establish linkages with health and social services, can be applied to the public education system. Research, such as the program to *Enhance and Evaluate Community Outreach in Pediatrics/Psychiatry and Education* (AB301-9), has demonstrated that schools can be effective sites for the delivery of a wide range of health and social services. Bringing services to the children and youth in their own milieu appears to be an effective strategy.

There are serious health human resource issues resulting from the increasing prevalence of mental health problems. Currently, there are long waiting periods for mental health care in traditional settings, unless a child is in crisis. This is complicated by the withdrawal of public health nurses and other professionals from the school setting in response to financial constraints in those sectors. COPE (AB301-9) demonstrates the effectiveness of cross-sectoral cooperation for identifying children with mental health care needs and for early intervention. Programs like COPE support the view that the school health system could be enhanced to meet these needs (public health nurses, for example, can play an important role in the early identification and referral of children to school-based mental health care workers with appropriate resources). Educators could also benefit from training in identification and referral.

Re-engineering the health care delivery system requires a broad range of knowledge and skills. Building the capacity of health care professionals is key to the success of the enterprise. The pace of the acquisition of new knowledge and the remarkable technological progress of the past few years have led to extensive changes in the training of the physician and nursing workforce. Unfortunately, little has been done with regards to improving medical professionals' awareness of the impact of non-medical health determinants on health and well-being. Conversely, social workers, psychologists, and education specialists

need to have opportunities to work collaboratively with biomedical personnel as responsible members of multidisciplinary teams aimed at improving the health and well-being of children and youth.

Redeployment of health professionals has continued as health care shifts from institutions to the community. Furthermore, redeployment implies the movement of health workers to non-clinical settings such as child care centres and schools. To ensure that redeployment is effective, and not done at the expense of quality of care, will require extensive field training and the creation of a system of linked multidisciplinary referral networks, allowing easy access without sacrificing quality.

## 5. Cross-Sectoral Implications of Children's Health

**T**here is an increasing recognition that the good or bad health of a mother and her child is related to social, cultural, economic, and lifestyle factors. No single service can do everything needed to support optimal maternal and infant health. Nevertheless, it would be ideal if a single service had the responsibility, expertise, and capacity to coordinate a broad range of services. There is a need for stronger communication among health care providers and social service providers. The health care system and the social services system must strive, collaboratively, to find a role for themselves in influencing the determinants of health.

Projects that establish functional links between health and social services, child care facilities, and schools are having positive results in terms of promoting population health. Partnerships between the child care sector, especially those elements offering early childhood education, and schools have the potential to ensure continuity throughout childhood. In fact, early childhood programs should not be taken in isolation and should be considered an essential part of anticipatory guidance and primary health care.

If there is a sector of health care where the partnership of parents, community workers, and health care providers is essential, it is the mental health sector. Parents need to participate at all levels of decision making because they and their communities are vital to successful interventions. Furthermore, communities need to identify appropriate delivery options locally. The integration of mental health care professionals into clinical settings where the health of children and youth with disabilities and chronic diseases are managed is a move in the right direction. However, there is still a long way to go before clinicians give proper weight to quality of life issues and to the repercussions of their interventions on the emotional and psychological development, and social integration, of their patients.

It was comforting to note that in the 28 reports dealing with child and youth health there was a great deal of attention paid to the dissemination of information and communication. This is important to build capacity in the voluntary sector. The Health Transition Fund should be congratulated for insisting on this dimension in the research.

## 6. Implications for Policy and Practice

**W**e have attempted to link the lessons learned from the four areas of child health research covered by the reports – pregnancy, birthing, and neonatology; child development; mental health; and integrated services – with recommendations specific to each theme as well as cross-cutting recommendations drawn from the 28 reports and from the evaluation and consultation process. These reports provide significant new knowledge that either confirms the appropriateness of certain existing interventions, suggests changes to better adapt programs to local conditions, or proposes innovative solutions.

However, in view of the small size of most projects, the limited time allocated, and the subjective nature of the data, there is a clear need for more evidence and particularly for the creation of a multi-centre research network modelled on networks such as the five Centres of Excellence for Children’s Well-being. Community-centred research is a *sine qua non* for innovative strategies and evaluation of existing programs. However, it will not provide the highest quality of evidence unless research is conceived and conducted by the functional integration of community service organizations, universities, government agencies, and the service recipients.

### 6.1 Recommendations Relating to Pregnancy, Birthing, and Neonatology

- As universal prenatal screening programs that include psychosocial issues can improve maternal and infant outcomes and are feasible, as demonstrated in *Enhancement of an Integrated Model of Prenatal Assessment and Care on PEI* (PE321), they should be developed and/or enhanced nationally.

- Strict national criteria for pregnancies with no identified risk factors should be developed for midwife-attended home births. The *Home Birth Demonstration Project* (BC404) provides information on both the positive aspects of home birth and the reasons for concern.
- Strong neighbourhood outreach and professional networking activities that help ensure that marginalized and vulnerable mothers and their babies have access to health and social services should be prioritized. This position is supported by “*Born Healthy, Raised Healthy*” – *A Breastfeeding and Nutrition Support Program* (SK323).
- Home visitation programs ensuring that all mothers and newborns are visited within 48 hours of discharge and for a minimum of six weeks postpartum can improve outcomes and should, therefore, be developed and/or enhanced nationally.
- Specially trained, multidisciplinary, hospital-based teams that follow-up low-birth-weight and very-low-birth-weight infants, as well as full-term infants with normal weights from families in difficulty, should be developed and/or enhanced nationally in order to improve outcomes as seen in the *Neonatal Transitional Care Program* (NA1017).

### 6.2 Recommendations Relating to Child and Youth Development

- Universal accessibility to high-quality child care facilities, which also deliver primary health and psychosocial services, should be established. The potential advantages of this approach are demonstrated in *Day Care Consultation Services* (SK329).
- Child development must be nurtured through family- and community-driven programs, such as the *Healthy Families Project* (AB301-21) or *Lloydminster’s “First Steps” Program* (SK328). Parent participation in early child development programs that enhance the child’s early learning and optimal development in the home environment is essential. Supporting these programs and



maintaining the component of parent participation should be a priority for all levels of government.

- *COPE* (AB301-9) illustrates how school health programs could be rebuilt so that they become a non-clinical setting for the delivery of a broad range of preventive, diagnostic, and therapeutic services. The “hub school” model should be broadly tested and evaluated and given high priority.

### 6.3 Recommendations Relating to Child and Youth Mental Health

- Increase research efforts aimed at a better definition of common mental health problems, such as attention-deficit disorder, hyperactivity, and autism and its variants, and ensure that high-quality services are available.
- Government funding to self-help groups should require these groups to demonstrate close linkages with mental health professionals. The value of collaboration between parents and professionals is clearly established in the *Autism Integration Project* (PE421).
- Provide immigrant, refugee, and Aboriginal children and youth with access to culturally sensitive mental health clinics. As indicated in *Development and Evaluation of a Cultural Mental Health Consultation Service* (QC424), these clinics can help overcome barriers to care.

### 6.4 Recommendations Relating to Integrated Services

- Establish criteria for what home care can do, taking into account the environment in which care will take place and the commitment and skills of caregivers. The need for careful consideration of these criteria is made evident by projects like *Home Chemotherapy for Children with Cancer: An Evaluation of Costs and Health Services Utilization* (NA132).

- Continue demonstration projects with well-constructed evaluations in the area of tele-home-medicine, such as *Tele-Home-Care: Multi-Site Modeling Component* (NA161). Set standards of care in advance of the proliferation of these kinds of health care programs.
- Link pediatric child and youth care networks to academic health sciences centres to ensure continuity, accessibility, and quality of care in a seamless transition from primary and secondary to tertiary care levels. The importance of this issue is evident in *Integrated Delivery of Youth Services in Quebec* (QC411).
- As user charges are an obstacle to the purchase of prescription drugs, it is recommended that access to free prescription drugs should be extended to working poor families. The importance of this issue is evidenced in *Monitoring the Effects of Family Health Benefits for Low Income Families in Saskatchewan* (SK331).

### 6.5 Recommendations that Cut Across Theme Areas

- There should be a seamless transition from hospital-based to community services, which requires high-quality communication and a clear commitment to the idea of hospitals without walls.
- The integration of primary, secondary, and tertiary care services with public health and community services will never be achieved until health care professionals are committed to, and trained in, the impact of health on the outcome and well-being of patients. Strategies should be developed to ensure this commitment.
- As there is an inextricable link between the quality of services and the quality of the knowledge and skills of those providing the services, priority should be given to ongoing professional development.

- Closer collaboration between government-funded and community organizations is a prerequisite to ensure effective and efficient delivery of services.
- Undue multiplication and compartmentalization of services presents a barrier to effective delivery of services. Efforts should be deployed to integrate services in order to achieve “one-stop shopping” for families.
- Non-clinical settings (workplaces, schools, child care centers, and other community buildings such as churches and community centres) should be used where possible for the delivery of health and social services to children, youth, and their families.

## 7. Conclusions

**O**verall, analysis of the 28 child health-related HTF-funded projects drives home the need to restructure primary health care to satisfy the following performance criteria:

- demonstrated ability to deliver the full range of primary care services to children and youth, including medical, nursing, social work, dental, psychological, and mental services;
- a clear strategy for meeting performance indicators set by the provinces; and
- proof of ability to provide or to connect clients with specialist care, laboratory services, foster home services, and hospital care.

Strategies for the involvement of families should be established at all stages from planning to implementation.

It is hoped that the Health Transition Fund and this synthesis report will increase understanding among the general public, health care providers, and policy-makers of the interconnectedness of research and comprehensive health care. Health policy decisions concerning Canada’s children and youth will continue to be powered largely by a greater community and user involvement in health care and child advocacy, but they still need to be based on objective evidence generated by robust research. This evidence base is urgently needed to support the development of a national vision for child and youth health and the strategies required to make it a reality.

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## Appendix A: List of HTF Projects Relevant to Children's Health

This appendix provides summary information on the HTF projects which were reviewed in the preparation of this document. For further information, please refer to the HTF website ([www.hc-sc.gc.ca/htf-fass](http://www.hc-sc.gc.ca/htf-fass)).

### **(NA132) Home Chemotherapy for Children with Cancer: An Evaluation of Costs and Health Services Utilization**

**Recipient: University of Toronto**

**Contribution: \$63,105**

This study compared a hospital-based chemotherapy delivery model and a home-based chemotherapy program by following 11 children, aged 2 to 16, with acute lymphoblastic leukemia (ALL). Treatment for ALL usually includes repetitive cycles of chemotherapy in hospital for a period of three years. The study's main goal was to see whether the quality of life for children and families was improved with home delivery without increasing adverse events, caregiver burden, or emotional stress. Cost-effectiveness and the acceptance of the service by families and health care staff was also evaluated. While noting that 11 children is too small a sample size to demonstrate significance, the study found that results of qualitative interviews found improvements in quality of life for both children and families with the home treatment and that home chemotherapy would appear to be safe and feasible. There was no difference in the nature and frequency of adverse events between home and hospital. Health care workers were generally supportive but were concerned about safety, accountability, qualified staffing, and ensuring that the home is still considered a "safe place" for the child with cancer when the home is also the locus of treatment.

### **(NA161) Tele-Home Care: Multi-Site Modelling Component**

**Recipient: The Hospital for Sick Children, Toronto**

**Contribution: \$87,240**

This report compares three regionally produced models of tele-home care, one (in Toronto) that was operational and the other two (in Calgary and St. John's) that were theoretical, pinpointing common elements and

noting site-specific differences. The project enlisted local hospital and home care personnel to develop the two theoretical tele-home care models by identifying broad service concepts, defining a patient population, pinpointing essential service elements, and making recommendations about technology requirements. The models were then compared with one currently being tested at the Hospital for Sick Children in Toronto. The project developed a "blueprint" for a core Canadian tele-home care service that could enable higher-intensity care in the home for up to six months after hospital discharge: establishing an audio-visual connection between the monitoring centre and the patient, monitoring patients at least once a day, and offering tertiary support to the patient and the community care provider. Tele-home care is an adjunct to, not a substitute for, traditional home care. The result was a better understanding of the nature, advantages, and adaptability of a new model of service delivery, which may increase health system efficiency but may also help resolve access issues for patients in rural and remote regions.

### **(NA1017) Neonatal Transitional Care Program Evaluation**

**Recipient: Calgary Regional Health Authority**

**Contribution: \$65,385**

This project evaluated a randomized clinical trial investigating the impact of a post-hospitalization support program for infants weighing less than 2,000 grams at birth. The study enrolled 135 low-birth-weight infants and randomly assigned them to the intervention/case group or control group, with a further stratification into low-birth-weight and very-low-birth-weight (less than 1,500 grams). Program personnel followed intervention-group infants for four months after they left hospital, providing anticipatory guidance and teaching within the home environment; control group infants received the standard public health nurse follow-up. Investigators found that improved infant and family outcomes can be realized when continuing support is provided. In particular, the intervention group received breast milk more frequently and for longer periods of time. Also, they received vitamin supplementation more appropriately and visited their physicians more regularly, with fewer unscheduled visits. No weight differences existed between the two groups at six months after discharge.

**(AB301) Alberta Primary Health Care Project****Recipient: Alberta Health and Wellness****Contribution: \$11,112,759 – 27 Studies**

This report is a meta-analysis of the 27 Alberta evaluation and demonstration programs. The projects addressed primary health care through six key strategies: rural/remote access, illness prevention and health promotion through community development, early intervention and education, system restructuring, integrated service delivery, quality improvement, and community health centre models. Findings from these projects contribute, in various degrees, to an understanding of the six national dimensions of primary health care. Some projects found that existing methods of payment to physicians discourage them from participating in interdisciplinary and multi-disciplinary activity. Many projects exemplified successful integrated service delivery and resulted in improved continuity of care. Others revealed a need for greater information sharing among providers, clients, public agencies, and administrators. Yet others emphasized the importance and benefit of early intervention and public awareness strategies. Rural projects demonstrated successful alternative strategies for advancing primary health care such as telehealth, “settlement nurses,” remote health teams, and immunization schedule monitoring. All projects completed individual reports and are accompanied by fact sheets and summaries.

**(AB301-9) Enhance and Evaluate COPE (Community Outreach in Pediatrics/Psychiatry and Education Program): A School-Based Primary Care Initiative**

This project looked at how to enhance and evaluate a school-based mental health program that identifies and diagnoses children with mental health problems. As well, the project investigated relationships between medical and school personnel and investigated the extent to which families were knowledgeable about their children's mental health. The project's ultimate goal was to reduce long-term social and health problems associated with the late identification of mental health problems. The study resulted in an earlier, more accurate, and more comprehensive diagnosis of children's emotional, behavioural, and learning difficulties. It also was found that the fee-for-service funding structure actively discourages physicians from working in school-based settings.

**(AB301-14) Healthy Families Primary Health Care Services to High-Risk Families**

This Capital Health Region project involved intensive home visits providing long-term services to families with their first child. It partnered with many community agencies, including public health centres, traditional healing societies, and child and family services to target families at risk of poor health outcomes for their children as a result of poverty or social factors. The project aimed to improve parenting by increasing parents' knowledge and use of community support and by assisting them in improving their personal development. It also sought to improve the child's health and development. The families involved expressed a high level of satisfaction with the services, as did staff and other stakeholders. The parents' knowledge of their children's development increased, and most parents said their relationship with their children improved because of the program. The study also noted a decrease in the number of infants being taken to emergency departments.

**(AB301-20) What Are the Client Characteristics and Their Perceived Barriers for Non-Adherence to Immunization Schedules and What Impact Will an Immunization Refusal Strategy Have on Subsequent Adherence at Six (6) Months, Twelve (12) Months, and Eighteen (18) Months?**

This project aimed to increase immunization rates in the Keeweenaw Lakes Regional Health Authority, a geographically large and culturally diverse region of 25,000 residents, almost 50 per cent of whom are Aboriginal. It hoped to increase immunization rates by inviting people who did not wish to update their child's immunizations either to sign a “refusal” form or to make an appointment for a subsequent immunization. It then followed up adherence at the 12-month, 18-month, and pre-school visit stage. Researchers found that parents' lack of knowledge about vaccines may be the most important single barrier to immunization. Lack of access to clinics was also a major factor. Other barriers to immunization included lack of child care and transportation problems. The project increased the region's immunization rates by about 20 per cent. The written refusal option was found not to be an effective strategy for dealing with under-immunization.

**(AB301-21) Healthy Families Project**

A home visiting program modelled on the United States' Healthy Families America program, this project provided long-term services to families with their first child. Participating families struggled with factors such as poverty, isolation, youth (many were teen parents), substance abuse, and violence. The goal of the project was to promote positive child-parent interaction, ensure healthy child development, support parents' functional development, and increase parents' knowledge of community supports. Participating families were linked with a "family visitor" who made weekly visits, providing parents with education, skill development, and links to community resources. Families rated the program excellent or good, and the program helped most families to use positive parenting strategies regularly. Overall, clients thought the program helped them become more confident in making community contact.

**(BC403) Eating Disorders Project North (EDPN)  
Recipient: Northern Interior Health Unit****Contribution: \$277,870**

This 18-month project sought to help physicians and residents of rural and remote communities better prevent and treat eating disorders close to home. It involved 30 communities and 385 participants. Organizers convened a committee of regional advisers on a monthly basis, used surveys to investigate community needs and resources, and then prepared and offered a variety of multi-day training sessions on prevention, intervention, and therapy. The study suggests a theoretical framework that could be integrated into a provincial/federal policy on eating disorders. The framework describes and promotes a more comprehensive and integrated approach to prevention, intervention, therapy, and diagnosis, and it makes the case for more resources for treating eating disorders.

**(BC404) Home Birth Demonstration Project****Recipient: British Columbia Ministry of Health  
and Ministry Responsible for Seniors****Contribution: \$167,400**

This project established the first systematic examination of planned home births in a regulated setting in Canada. When British Columbia began regulating midwifery in January 1998, midwives and their clients were required to participate in this project, which ran until October 2000. A multi-stakeholder advisory committee developed midwife protocols and a data collection system and then dealt with emerging issues and recommendations. An independent evaluation team identified negative situations and forwarded the cases to a panel of clinical experts, which identified practice and integration issues. In the study, data from 862 planned home births were evaluated and compared with 743 planned low-risk hospital births attended by a physician and 571 planned hospital births attended by a midwife. Researchers found that midwives are able to appropriately screen women, are cautious practitioners of home birth, and cooperated well with other health care workers. Planned home births compared favourably with – and sometimes outshone – hospital births with respect to postpartum hemorrhage rates, infections, and rates of inductions, episiotomies, and other interventions. However, some cases of obstetrical shock, and three of the four incidents of perinatal death, occurred during home births. The authors caution that the sample size was not large enough for valid statistical comparisons of risks.

**(BC422) Integrated Postpartum Care and Lactation Support****Recipient: North West Community Health Services Society****Contribution: \$63,037**

This project developed a partnership between an acute care hospital and public health services to provide postpartum care in an isolated, semi-urban, northern community in British Columbia. The project was undertaken in response to concerns about the effects of early discharge from hospital on postpartum outcomes, particularly breastfeeding. Women could attend a clinic seven afternoons a week or receive a home visit during the first two weeks postpartum. Topics addressed at the clinic included breastfeeding, baby development, family adjustment, and links with other services. Client satisfaction was high, and health care providers expressed confidence in the service. However, the 12-month time frame did not permit an evaluation of health outcomes.

**(NB301) Analysis of School Readiness Data****Recipient: Department of Health and Community Services, Government of New Brunswick****Contribution: \$25,000**

This study evaluated New Brunswick's Early Childhood Initiatives (ECI) Program, with its range of services including pre- and post-natal screening, day care, and crisis intervention. Its goal is to give children a healthy start in life and to improve their "school readiness." Researchers analyzed data from Statistics Canada's National Longitudinal Survey of Children and Youth (NLSCY) and then compared New Brunswick's prevalence of children from birth to age five with poor social, behavioural, or cognitive outcomes with those children in the rest of Canada. They also assessed whether the number of vulnerable children in New Brunswick declined over the period studied. The study found significant declines in the proportion of premature and low-birth-weight babies as well as in babies with low motor and social development. The prevalence of prenatal complications remained higher than the national average. Probably the most significant finding was that although New Brunswick children improved their vocabulary over the two years, they were still 28 per cent more likely to have low vocabulary scores than were children in the rest of Canada, a fact attributable to the relatively lower socio-economic status of New Brunswick families.

**(NS401) Sharing Strengths: A Child and Youth Health Strategy****Recipient: Western Regional Health Board****Contribution: \$458,600**

Starting from a population health approach, this project worked with communities in western Nova Scotia to improve the health of their children and youth. With support from the Sharing Strengths project, Community Health Boards (CHBs) and local organizations identified existing resources, defined priorities, and developed strategies for action. This project provided logistical support for initiatives aimed at promoting physical activity for young people and emphasized the contribution of skilled and educated leaders to community capacity. Sharing Strengths also helped found a working group (with representation from government, non-governmental sectors, justice, recreation, and so on) to identify and address child and youth issues. The project participated in the development of an integrated database that will establish a baseline measurement of child and youth health in the region and thus allow the monitoring of changes in health indicators. Researchers also began to develop ways of measuring changes in community capacity building and resiliency.

**(PE321) Enhancement of an Integrated Model of Prenatal Assessment and Care on Prince Edward Island****Recipient: Prince Edward Island Department of Health and Social Services****Contribution: \$100,000**

This project promoted interventions during pregnancy to prevent risks to the newborn, the mother, and the family. Researchers used an existing prenatal psychosocial assessment model and then held education sessions for 73 physicians on how to conduct enhanced assessments. Referrals were made to appropriate community services that agreed to inform physicians about their clients' outcome. Interventions included counselling on breastfeeding, mental health, nutrition, stress, and smoking cessation. After a three-month period, participating physicians reported that they were satisfied with the education sessions. Although there was little change in the number of referrals or in the ease of access to clients, physicians became more aware of services, and communication between doctors and patients improved.

**(PE421) Autism Integration Project****Recipient: Prince Edward Island Department of Health and Social Services****Contribution: \$171,831**

This two-year initiative aimed to improve treatment services for children with autism and their families by reducing dependency on out-of-province agencies and the need for long-term interventions. The project established a parent/professional committee to oversee the integration of services and train an autism program specialist. The project also set up a rotating autism clinic that brought together pediatric services, child psychology specialists, speech/language services, occupational therapists, and autism program specialists. Researchers concluded that the new model reduced parental stress and improved service delivery. Parents said that their children's physical, mental, social, and language skills improved. However, they also said the responsibilities of training and supervising in-home workers was extremely demanding.

**(PE422) Provincial Social Support Program for Teen Parents****Recipient: Prince Edward Island Department of Health and Social Services****Contribution: \$137,500**

This two-year project helped teenage parents access social, educational, legal, and health supports. With a provincial mandate, the project coordinator worked at the grassroots level with teenaged clients in five health districts to define needs, objectives, and service gaps and then integrated existing service networks and raised the level of awareness of teenage parent issues among regional service providers. During the project, new information resources were prepared and disseminated. The project highlighted a lack of continuity in services for teenage parents and the need for a systematic approach to meeting their needs in the employment, legal, social, and education sectors. The project saw a 10 per cent increase in participants staying in school, increased teenage parent access to services, and increased networking among service providers.

**(QC305) Supraregional Mother-Child Network****Recipient: L'Hôpital Sainte-Justine****Contribution: \$2,278,514**

This project established a "mother-child network" among hospitals in four health regions in Montréal and the surrounding area, reaching into rural areas north of the city, to lighten the burden on urban centres by shifting primary and secondary care to hospitals close to patients. The project used telemedicine technologies and telehealth training for practitioners. Clinical practice was reorganized to care for mothers and children in hospitals near their home, and the project developed coordination mechanisms to ensure a continuum of care during the transfer process. The evaluation of the project records some success, particularly at the level of operational coordination. The telemedicine aspect of the project also improved access to services in isolated areas where qualified doctors were rare. No estimate of cost-effectiveness could be done because of current data-collection practices. The authors note that one of the most intractable obstacles was that parents preferred to go to a hospital emergency department because they knew they could find pediatricians there. During the short time period of the study, access patterns did not change significantly.

**(QC410) Transformation of Community Organizations' Practices in Connection with the Reorganization of the Health and Social Services Network****Recipient: Université du Québec à Montréal****Contribution: \$253,946**

A major reorganization of Quebec's health and social service network more than 10 years ago defined a new role for community organizations. This study relates to health in its wider sense (population health determinants, promotion, and prevention) by describing the current practices in community organizations in three sectors: families, youth, and women. Using case studies and a widely distributed questionnaire, the researchers looked at aspects such as programs, governance, partnerships, financing, and evaluation. They then examined the impact of changes in the health and social services system (regionalization, participative decision-making, a continuum of services, complementarity) on community organizations. They conclude that community organizations have



an increasing role in Quebec society and that the changes they have undergone are at least partially due to the role they play in the newly reorganized services. The researchers recommend more stable funding to support this new role; they emphasize, as well, the need to maintain autonomy of action in recognition of the specific expertise and particular approach that characterizes community organizations.

**(QC411) Integrated Delivery of Youth Services in Quebec**

**Recipient: Le centre jeunesse de Québec**

**Contribution: \$1,684,965**

Part one of this four-part study describes services provided to children and youth under the authority of *Centres de jeunesse*. The researchers point out the need for better assessment instruments and more coordination to link the client's situation with the intervention chosen. They also note the high rate of poverty, social isolation, and mental health problems among parents of children placed in *Centres de jeunesse*. This is the first study of this population, and it establishes a baseline portrait from which to continue analysis. Part two describes how plans for intersectoral collaboration work in practice and concludes that explicit mechanisms for collaboration must be elaborated by organizations. Part three recommends clarification of the rights and responsibilities of parents concerning placement and their increased involvement. Part four evaluates the changes (begun in 1997) in the delivery of services to youth in *Centres de jeunesse* in Montréal and Quebec. The researchers observe that conditions for change were not present in the *Centres de jeunesse* studied, and they make recommendations about what those conditions might be.

**(QC424) Development and Evaluation of a Cultural Mental Health Consultation Service**

**Recipient: Sir Mortimer B. Davis Jewish General Hospital**

**Contribution: \$449,676**

This project involved the development and evaluation of cultural consultation services in the field of mental health in three hospitals in Montréal, including a children's hospital. The goal was to improve access to culturally appropriate mental health services for patients from a range of cultural backgrounds,

including immigrants, refugees, various ethnocultural groups, and First Nations and Inuit patients. One of the sites offered only consultation to other practitioners; the others provided treatment as well. They all used the services of interpreters and "cultural brokers" to overcome the barriers to communication. The evaluation showed that a culturally sensitive intervention improved assessment and treatment. The project also developed a database of community resources and a Web site with links to other sites related to cultural competence.

**(SK322) Roots and Wings: Prevention of Child Abuse/Neglect**

**Recipient: University of Saskatchewan**

**Contribution: \$280,246**

This project implemented prenatal screening of primiparous women as a means of identifying first-time parents at high mental health risk of abusing or neglecting their infants. It also evaluated a post-natal home-visitation intervention program for high-risk parents that involved intensive home-visiting by trained professionals and that was fully integrated with existing community services. As well, the project sought to reduce the heavy burden placed by this target group on all levels of the health care system. The researchers developed a screening tool that appeared to be effective in identifying a high-risk group that other service providers had indicated was not being served. One of the key findings was that a high mental health risk for child abuse and neglect is not related to age, income, ethnic background, or marital status, although high- and moderate-risk groups had completed fewer years of education than had the low-risk group.

**(SK323) "Born Healthy, Raised Healthy," a Breastfeeding and Nutrition Support Program**

**Recipient: Battlefords Health District**

**Contribution: \$191,733**

This project aimed to improve maternal and infant health in the Battlefords Health District community by establishing a supportive breastfeeding and prenatal nutrition culture and improving client access to health care services. The targeted population included teen parents, single mothers, low-income families, and transient females. Many were Aboriginal people. Services were provided by a project coordinator/lactation consultant and outreach

workers in a street-front outreach centre. This project increased the target population's ability to access services, improved their food security, addressed determinants of health such as social and physical environments, and created more community resources. The project was valued by clients and partners for its ability to make a positive difference in population health. Most importantly, clients who received support had higher rates of breastfeeding than did a sample of non-project mothers who self-reported their breastfeeding rates.

**(SK324) An Evaluation of Integrated Services for Families of Aggressive School-Aged Children**

**Recipient: Battlefords Health District**

**Contribution: \$171,600**

This project provided mental health services to aggressive school-aged children by moving those services from institutions to schools, homes, and the community. In doing so, it hoped to integrate services and reach children who are traditionally overlooked. The study involved 13 children from “multi-problem” families; the majority were of First Nations ancestry, male, and living in single-parent families or extended families. Most lived in lower-income households, all exhibited aggressive or defiant behaviour, and many were felt to be at risk for criminal conduct. Mental health professionals and social workers involved teachers, school administrators, and families, and services were provided after-hours and in a variety of non-conventional settings. A qualitative review of the data concluded that 10 of the 13 children experienced a positive change in their behaviour, but these results could not be confirmed in a quantitative review.

**(SK328) Lloydminster's “First Steps” Program**

**Recipient: Lloydminster Health District**

**Contribution: \$153,096**

This pilot project provided support, information and resources to 42 at-risk families who had children under the age of three. Through direct home visits, group activities, public education, and referrals to community services, it strove to enhance the development of children served, to empower families to take responsibility for their developmental needs, and to demonstrate the effectiveness of integrated service delivery. An independent consultant evaluated the program and found that it had, with varying degrees of success, achieved its three goals.

**(SK329) Day Care Consultation Services**

**Recipient: Saskatoon District Health**

**Contribution: \$140,000**

This project aimed to overcome traditional barriers to mental health services for 112 at-risk pre-school-aged children in day-care settings. It also set out to increase the skills and knowledge of 91 child-care workers in dealing with children who exhibit aggressive or non-compliant behaviour. The project hired two full-time behavioural consultants, who provided assessments, referrals, support, and workshops for families and community staff. In addition, a group of community stakeholders met monthly to monitor and provide feedback to the team. Evaluation of the project suggested that these children, their families, and child-care workers benefited from the project. The children's behaviour improved, they received better access to services, and staff said that they learned much. Over half of the parent respondents said they learned better ways of dealing with their children's behaviour at home. Overall, the model fit those in child-care centres better than it did those in family-care homes or infant centres.

**(SK331) Monitoring the Impact of Family Health Benefits for Low-Income Families**

**Recipient: Saskatchewan Social Services**

**Contribution: \$113,345**

This study examined how both families on welfare and low-income working families used a provincial health benefits program, and how a change in the forms of coverage provided changed their use of health services. Family Health Benefits (FHB) is a Saskatchewan supplementary health plan designed to reduce the financial impact of children's health services on low-income families and thus to prevent potential health costs from deterring parents from becoming employed. Under FHB, working poor families receive several health benefits that had previously been available only to families on welfare. Three services – chiropractic, prescription drugs, and optometry – were examined. The study found that families on welfare used health services more than did new recipients of the FHB program designed for the working poor.

**(SK332) Parenting Plus: Early Childhood Development Program****Recipient: Pipestone Health District****Contribution: \$186,991**

This program is modelled on Hawaii's Healthy Start Program and had four components: the systematic screening of families of newborns to determine those families or mothers at risk of abuse or neglect; a series of home visits; informal community support; and improved coordination of services. The project took place in the rural Pipestone Health District, between Regina and the Manitoba border. A total of 136 mothers was screened. Of the 26 found to have a positive assessment, 18 enrolled in the program. These families were primarily headed by single mothers, of whom about two thirds were under the age of 25. The majority were unemployed and had education below grade 12, indicating that the project seemed to be hitting its target audience. The program is continuing and has received partnership funds from SaskTel. The report notes the challenge of providing the program within cost to a rural environment, where extensive travel is needed.

**(SK334) Developmental Program Evaluation: Planned Parenthood Regina Sexual Health Centre****Recipient: University of Regina****Contribution: \$166,665**

This report evaluated the Planned Parenthood Sexual Health Centre in Regina, which has seen its annual number of clients quadruple in five years. Although the study found that the majority of physicians and counsellors (more than 80 per cent) in the region were aware of its existence, just over half of them knew about the full range of services it provided. The awareness among teens was much less: 31 per cent had "never heard of it," and 80 per cent did not know where it was. However, a survey found that the centre had established a positive image among its users that included a record of caring, confidential, and cost-effective service. The report's findings (e.g., by grade 12, 44 per cent of all students have had intercourse, and a majority of them were uninformed about the best way to prevent pregnancy and sexually transmitted diseases) makes it clear that there is a need for a continued focus on sexual health education.

**(SK423) Integrating Services for Families with Affective Disorder: Implementing and Evaluating a Preventive Intervention Program in Saskatchewan****Recipient: Prince Albert Health District****Contribution: \$127,750**

Children of depressed parents are at a significant risk of developing psychiatric disorders in childhood or adolescence. This study implemented and evaluated two preventive intervention strategies and modified them for use in the Prince Albert Health District. The intervention was either a series of family meetings with a clinician about depression issues and family functioning or a lecture that covered similar material but did not include the child or family discussion. The evaluation found that brief, family-based intervention was satisfying and helpful to the patient and family. Up to six months after the completion of the project, 94 per cent of depressed patients and 78 per cent of spouses were moderately to extremely satisfied with both the lecture and the clinician intervention. The researchers found no significant difference between the outcomes of the lecture group or the clinician-facilitated group.

