

# THE COMMUNITY PERINATAL CARE

# FOLLOW UP STUDY



SCREENING FOR DEVELOPMENTAL PROBLEMS AMONG PRESCHOOL-AGED CHILDREN



Prepared for The Calgary Children's Initiative

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### **REPORT PREPARED BY:**

#### Dr. Suzanne Tough, PhD (Principal Investigator)

Associate Professor, Departments of Pediatrics and Community Health Sciences University of Calgary Room C4-301, Alberta Children's Hospital 2888 Shaganappi Trail, N.W. Calgary, Alberta T3B 6A8 Telephone: (403) 955-2272 Fax (403) 955-2404 Email: suzanne.tough@calgaryhealthregion.ca

#### Jodi E Siever, MSc (Biostatistician)

Analyst, Decision Support Research Team Room C4-314, Alberta Children's Hospital 2888 Shaganappi Trail, N.W. Calgary, Alberta T3B 6A8 Telephone: (403) 955-2387 Fax (403) 955-2404 Email: jodi.siever@calgaryhealthregion.ca

### Karen Benzies, RN, PhD (Co-Investigator)

Associate Professor, Faculty of Nursing 2500 University Drive NW Calgary, Alberta T2N 1n4 Telephone: (403) 220-2294 Fax (403) 284-4803 Email: Benzies@ucalgary.ca

#### Shirley Leew, , *PhD*, *CCC-SLP*, *S-LP* (*C*) (Co-Investigator)

Clinical Research Associate, Decision Support Research Team Room C4-314, Alberta Children's Hospital 2888 Shaganappi Trail, N.W. Calgary, Alberta T3B 6A8 Telephone: (403) 955-7569 Fax (403) 955-2404 Email: shirley.leew@calgaryhealthregion.ca

#### David W Johnston, MA (Co-ordinator)

Research Coordinator, Decision Support Research Team Room C4-314, Alberta Children's Hospital 2888 Shaganappi Trail, N.W. Calgary, Alberta T3B 6A8 Telephone: (403) 955-2383 Fax (403) 955-2404 Email: davidw.johnston@calgaryhealthregion.ca

Questions about this research can be directed to Suzanne Tough at the contact information provided above. Requests for copies of this report can be directed to **The Calgary Children's Initiative, (403) 231-6287** <u>info@childrensinitiative.ca</u> or can be found on these websites: <u>http://www.calgaryhealthregion.ca/dsrt/reportsandposters.htm</u> <u>http://www.childrensinitiative.ca/index.asp</u>

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## **Executive Summary**

### BACKGROUND

The Community Perinatal Care (CPC) Study was initiated by the Conception to Age Five Working Group of The Calgary Children's Initiative. The working group consisted of representatives from the Calgary Health Region, City of Calgary, child and youth serving community agencies, Calgary Board of Education, Alberta Health and Wellness, University of Calgary, Mount Royal College, and immigrant serving agencies. The Working Group developed the study to address the goal of The Calgary Children's Initiative that *"All babies are born healthy" and to address the recommendations from a Calgary Health Region report which suggested that redesign of prenatal care may lead to improved access to resources.* 

The CPC study was a prospective randomized controlled trial of pregnant women attending one of three family physician low risk maternity practices within the Calgary Health Region. 2,015 women were randomly assigned to receive one of the following: 1) standard of care at the prenatal clinics (control); 2) standard of care plus consultation with a registered Nurse: or 3) standard of care plus consultation with a Nurse and a Home Visitor. Participants completed a baseline interview, as well as interviews at mid-pregnancy and eight weeks post-partum. The primary results showed that, compared to women in the control group, women who had Nurse or Nurse plus Home Visitor supports were more likely to:

- 1) Use community-based resources (such as prenatal classes, parenting classes, breastfeeding supports, nutritional counseling).
- 2) Report having a health care worker provide information on pregnancy-related topics.

The full results of the CPC study can be found in an earlier report<sup>1</sup>.

Approximately three years post partum, a follow-up telephone questionnaire was conducted with the original CPC cohort. The questionnaire was designed to learn about parenting, child health, development, health care utilization, and well-being. Data from the CPC follow up questionnaire are the subject of this report.

### **OBJECTIVES**

The primary objective of the follow up study was to address the following question:

 What parental and environmental factors are most strongly associated with child developmental screening results, reported by the Parents' Evaluation of Developmental Status (PEDS)<sup>2</sup>, amongst children who were delivered to medically low risk pregnant women?

The secondary objectives were to answer the following questions:

- 1. What are the characteristics of children and families that are related to positive child outcomes (as measured by the PEDS) in the presence of risk (low income, non-Caucasian, low education, etc.)?
- 2. What is the utility of using telephone contact to administer a standardized child development assessment form to parents of preschool aged children in Calgary?

### **METHODS**

All eligible mothers from the initial CPC study who agreed to participate in follow up studies were contacted and invited to complete a 15-20 minute telephone questionnaire. All interviews were conducted through the Population Research Laboratory, University of Alberta, and all mothers who participated gave verbal informed consent. The questionnaire addressed child development, child care, medical care, health of the child, mother's lifestyle, mother's emotional and physical well-being, and parenting style.

Both a pilot test and pre-test were conducted in order to test the instrument for wording, transitional statements, additional instructions, flow of questions, and length of the questionnaire. The study was launched on November 30, 2005 and was completed on March 27, 2006.

## **HIGHLIGHTED RESULTS**

### **Recruitment and Completion Rate**

In total, 1,147 mothers from the CPC cohort were eligible for this follow up study. 791 of these mothers completed the telephone questionnaire, resulting in a 69% completion rate. Mothers who could not be reached were more likely to be less than 25 years of age, smoke, have required food bank support, scored low on scales that assess ability to seek help and to have scored low on self esteem during pregnancy. Consequently, these findings may not be generalized to all children and families in Calgary.

### **Primary Outcome**

There were 86 children (11%) in the study who were identified by the PEDS screening tool as having a high risk for developmental problems. There was no significant difference between CPC study groups, with 33 (10%) in the Control group, 19 (9%) in the Nurse group, and 34 (13%) in the Nurse plus Home Visitor group being identified by the PEDS as having a high risk for developmental problems. Of these 86 children, 43% had been referred for further evaluation.

Of those (n=86) who were identified as having a high risk for developmental problems, these children were significantly:

- More likely to be male
- ♦ More likely to have had ear infections prior to age two
- ◆ More likely to have had a referral to one or more of the following:
  - Early intervention program
  - Speech and language pathologist
  - Developmental pediatrician
  - Psychologist
- ◆ More likely to come from single parent families or families with a low annual income
- + More likely to have a mother with a history of poor mental and emotional health
- More likely to have a mother with feelings of low parenting morale



### **Secondary Outcomes**

Three subgroups of mothers were examined, including those with a history of poor mental health (N=391), current poor mental health (N=154), or demographic risk (e.g. low income, young maternal age) (N=129), to determine if there were characteristics of mothers that distinguished children with low risk of developmental problems from children with high risk of developmental problems. The characteristics of mothers with children who were at low risk of developmental problems included:

- 1. Among mothers with a history of poor mental health:
  - Relaxation and contentment during pregnancy
  - High parenting morale post partum
- 2. Among mothers with current poor mental health:
  - High parental expectations during pregnancy
  - Had taken a parenting class
  - Low distress post partum
  - Less likely to feel depressed and/or anxious during pregnancy

### 3. Among mothers with demographic risk:

- High parenting morale post partum
- Had taken a parenting class
- Low distress during pregnancy
- Relaxation and contentment during pregnancy





### **Key Conclusions**

Although most children in this follow up study were healthy and meeting developmental milestones, more than half of the children who screened at high risk for developmental problems had not been previously identified or referred for further assessment. The characteristics of children and families more likely to screen at high risk for developmental problems by the PEDS included male infants, infants with ear infections prior to the age of two years, infants from families with a low income or single parents, infants with mothers who had a history of poor mental and emotional health, and infants with mothers who had low parenting morale. There is an opportunity to better understand the relationship between risk factors and outcomes, and, as importantly, to identify families and children at higher risk for developmental problems in order that appropriate services and support be provided to encourage optimal child development.

Parents rely on primary health care providers for physical and developmental assessment of their infants and preschool children. Primary care providers have identified significant barriers to the implementation of universal developmental screening, including the time involved, limited reimbursement for screening efforts, and their perception that existing measures or parent concerns are inaccurate or unreliable, especially when a child is very young<sup>3, 4</sup>. The implementation of a quick, simple and effective screening tool has the potential to greatly improve the early detection of developmental problems, with the potential for earlier intervention and improved long term outcomes for children.

### **Key Points**

- 1. Of those mothers who participated in the follow up study, the majority were married with household incomes in excess of \$40,000 per year. A total of 40% of mothers reported that a parent stayed home full time until the child was at least 2 years old, and over 45% reported providing breast milk for at least 6 months. Currently, 60% were working part or full time at a paid job and almost half of the mothers had been pregnant again since the CPC study. Although the majority of mothers reported their current physical and emotional health as good to excellent, 35% self reported two or more weeks of depression after the birth of their infant.
- The majority of pre-school children were spending less than 2 hours per week in structured extra-curricular activity, and almost 90% of children were read to at least daily.
- 3. Using the PEDS, 11% of children screened at high risk of developmental problems. Among these 86 children, 43% had been referred for services. Thirty percent of children screened at moderate risk of developmental problems, 24% at risk of mental health concerns and 35% screened at low risk of concern.
- 4. Children who screened at high risk for developmental problems (PEDS Path A) who had been referred to services or follow up were more likely to have been born preterm (<37 weeks completed gestation), to have had their hearing tested, and to have vision problems compared to children who screened at high risk of problems who had not been previously referred. The primary referral was to a speech and language pathologist.
- 5. Male children were identified as having twice the risk of developmental problems. Additional factors that increased the risk of developmental problems by 40% to 90% included children born to mothers who had a history of abuse or depression prior to

pregnancy, who experienced distress and lack of well-being during pregnancy or who lived in homes with a household income <\$40,000 per year.

- 6. Among those mothers with past poor emotional health, current poor emotional health, or demographic risk, factors that in general distinguished families of children at low risk of developmental problems from those with high risk of problems included: positive feelings during pregnancy, lower overall distress during pregnancy, higher parent morale post partum, and having attended a parenting class.
- 7. The majority (over 80%) of mothers were obtaining parenting information from the television, with less than 25% reporting attendance at parenting classes or seminars.
- 8. Mothers indicated that their first choice for screening venue would be at a physician's office. They would prefer that screening was conducted by a face-to-face interview.

### **Key Recommendations**

- 1. Telephone follow up to screen for developmental problems using existing physician or hospital data bases is apt to miss children who live with younger mothers who smoke, use food banks, or have low self esteem. This analysis suggests that these mothers are also at higher risk of having a child with developmental problems.
- 2. Children at high risk for problems who are not born preterm are at risk of underidentification. However, over 90% of these children are seen for routine check ups and immunization. These routine check ups and immunizations visits may be missed opportunities for regular and repeated developmental screening in settings where mothers already take their children. Routine screening as a component of well child immunization visits warrants serious consideration.
- 3. Demographic and mental health characteristics of mothers whose children are at high risk of problems may be identifiable during pregnancy and prior to delivery (e.g. histories of abuse, distress, and depression). There is an opportunity to develop programs that improve the health and well being of mothers which ultimately may have a positive impact on child development. Such programs could begin in the prenatal period and continue through early childhood and be designed to address self esteem, the ability to seek and obtain help, parenting skills and morale.
- 4. Among women with mental health and demographic risks, those who had feelings of relaxation and contentment during pregnancy, who had lower overall distress and higher parenting morale were less likely to have a child who screened at high risk of developmental problems suggesting that efforts to improve emotional health and well being prior to delivery may reduce the likelihood of adverse developmental outcomes. Furthermore, those women who had attended a parenting class were less likely to have a child who screened at high risk for problems, suggesting that efforts to enable women to obtain information about pregnancy and parenting may be important to enhance optimal child development.
- 5. Given the high proportion of parents who indicate they obtain parenting information from television, this medium should be considered for the delivery of evidence-based information on parenting and child development.

- 6. The feasibility of routine developmental screening in a primary care setting should be pilot tested. In addition, methods to complete screening instruments (face-to-face interview with physician versus parent-completed screen) should be explored.
- 7. Preliminary results suggest that 41% of children would benefit from further assessment of development (11% at high risk and 30% at moderate risk), while 24% of mothers may require additional support to address mental health and behavioural issues. Routine/universal screening would require appropriate downstream support for children and families prior to implementation. The World Health Organization has guidelines to aid with decision making in this regard.

## Introduction

### **BACKGROUND TO THE COMMUNITY PERINATAL CARE STUDY**

The Community Perinatal Care (CPC) Study was initiated by the Conception to Age Five Working Group of The Calgary Children's Initiative. The working group consisted of representatives from the Calgary Health Region, City of Calgary, child and youth serving community agencies, Calgary Board of Education, Alberta Health and Wellness, University of Calgary, Mount Royal College, immigrant serving agencies, and others with child development expertise. The Working Group developed the study to address the goal of The Calgary Children's Initiative that "All babies are born healthy".

Early in the process, it became apparent that the goals developed by the working group for the CPC Study were commensurate with some recommendations of the 1997 Maternal-Newborn Program Design Committee of the Calgary Health Region<sup>5</sup>. The final report of this committee highlighted the need for integrated service delivery that would be more responsive to consumer needs and better coordinated among service providers and agencies. Recommendation five of the Committee was the development of a region-wide voluntary pregnancy registry for maternal-newborn services, defined as a "Notification of Pregnancy" program<sup>5</sup>. Recommendation six was to redesign the role of the community health nurse in prenatal care. Recommendation seven was to complement and augment the practice of community-based family physicians. The recognition and appreciation of the CPC Study in 2004.

## BACKGROUND TO THE CPC FOLLOW UP STUDY

The CPC follow up study builds on the original CPC Study cohort to answer important population health questions related to child health and development. The cohort represents a generally well-educated, affluent group of Calgarians for whom extensive data has already been gathered and analyzed. These results provide insight into what is currently happening in our community in terms of perinatal care and outcomes. The CPC follow up study adds additional information about child developmental screening, early intervention referral rates, longer term outcomes, and is the subject of the remainder of this report.



## Rationale for the CPC Follow up Study

Parents rely on primary health care providers (physicians and public health nurses) for both physical and developmental assessment of their infants and preschool children. Because physicians and public health nurses are in regular contact with children from birth, they are often aware of familial, social, and environmental factors that may be affecting the child's development<sup>6</sup>. Therefore, primary care providers play critical roles in the early identification of risks to development.

In Canada and the U.S, the prevalence of developmental disabilities is reportedly between 12% and 17%<sup>3, 4</sup>. However, the common practice among primary care providers to assess development and behaviour is brief clinical observation which identifies only 30-50% of children with delay<sup>3,7</sup>. Under-detection might be the result of some primary care providers' unfamiliarity with important subtleties of early childhood development, or because they have limited time and resources to assess development, provide counseling, and make appropriate referrals<sup>8,3,4</sup>. Some perceive that existing measures or parents' concerns are inaccurate or unreliable, especially when a child is under three years of age. Consequently, mild to moderate developmental problems are at risk of remaining undetected until school age, resulting in missed opportunities for early intervention programs that may ameliorate delays and provide opportunity for optimal development<sup>9,10</sup>.

Pediatricians, family doctors, and public health nurses need tools and strategies to efficiently and accurately identify risks and to appropriately refer children to early childhood developmental programs. Appropriate changes in screening and referral practices by primary care providers have the potential to greatly improve the effectiveness of developmental surveillance, with the added benefit of improved lifetime outcomes for children.



## Objectives

## **PRIMARY OBJECTIVE**

The primary objective of the CPC follow up study was to address the following question related to assessing child development amongst preschool aged children:

1. What parental and environmental factors are most strongly associated with developmental screening results, reported by the Parents' Evaluation of Developmental Status (PEDS)<sup>2</sup>, amongst children who were delivered to medically low risk pregnant women?

## SECONDARY OBJECTIVES

Other objectives of the CPC follow up study were to answer the following questions:

- 1. What are the characteristics of children and families that are related to positive child outcomes (as measured by the PEDS) in the presence of risk (low income, non-Caucasian, low education, etc.)?
- 2. What is the utility of using telephone contact to administer a standardized child development assessment form to parents of preschool aged children in Calgary?



## **Methods**

This follow up study was built on the initial CPC cohort of women, for whom extensive demographic information has already been gathered. For complete CPC study methods, please refer to the Community Perinatal Care Study Final Report<sup>1</sup> or Appendix 1 of this report.

### DESIGN

Those mothers who participated in the CPC study, and who agreed to participate in follow up studies (94% of CPC completers) were contacted by telephone when their child was between 18 months and 4 years old and invited to participate in the follow up study.

### RECRUITMENT

All women from the initial CPC cohort who could be contacted and who agreed to participate in follow up study completed a 15-20 minute telephone questionnaire conducted by the Population Research Lab (PRL) in Edmonton, Alberta. The PRL has extensive experience and success with implementation of computer assisted telephone questionnaires (CATI). Before administering the questionnaire, the respondents were informed by the interviewers that their participation was voluntary, that their responses would be linked to the original CPC data set, and information they gave to the research study would be kept confidential. Respondents had the right to terminate the interview at any time.

The main study was launched on November 30, 2005 and was completed on March 27, 2006. Interviews and callbacks were scheduled both during the day and evenings from Monday to Sunday. Telephone supervisors monitored the work of the PRL interviewers.

### **INCLUSION/EXCLUSION CRITERIA**

Women who participated in the CPC study and indicated at the time of enrollment that they would be willing to participate in future research were eligible for the follow up study.

Women who miscarried, did not speak English, did not currently reside in the city of Calgary at the time of recruitment, or who had an incorrect phone number were excluded.

## DATA COLLECTION

Before recruitment commenced, the telephone interviewers and supervisors received extensive and comprehensive training. Prior to data collection, the PRL received the database of CPC participants for the study and loaded it into the CATI system. The database contained 1629 eligible women from the original CPC study.

## **COMPONENTS OF THE QUESTIONNAIRE**

The telephone questionnaire took approximately 15-20 minutes to complete and included information on the following topics:

- Child Characteristics
  - Date of birth, gender, height / weight, weeks gestation at birth, breastfeeding, siblings and birth order
- Medical / Health of the Child
  - Parent Evaluation of Developmental Status (PEDS)<sup>2</sup>, family doctor, routine physical exam, routine vaccinations, referrals (early intervention program, speech and language pathologist, child development pediatrician, psychologist, physiotherapist, dietician), hearing and vision testing, dentist, chronic medical conditions, rating of child's health



- Child Care / Child Activities
  - Type of child care, hours per week in scheduled activities
- Mother's Characteristics
  - Marital status, spouse/partner, education, income, work, food and housing security, smoking, alcohol, drugs, physical and emotional health, depression, abuse, relationship with partner, social support
- Parenting
  - Parent morale (Parenting Morale Index)<sup>11</sup>, type of parenting (NLSCY positive parenting interaction, NLSCY hostile/ineffective parenting and aversion scales)<sup>12</sup>, parenting information

A description of the standardized measurement tools included in the questionnaire can be found in Appendix 2. A copy of the full questionnaire can be found in Appendix 3 (separate document).

## **PEDS COMPONENT**

The PEDS is an evidence-based 10 item parent report screening measure designed to facilitate parent-professional communication about development and to ensure that development and behaviour problems in children birth to 8 years of age are detected and addressed<sup>2</sup>. This is done by eliciting parent concerns, determining children's level of risk for disabilities, and identifying the optimal professional response.

The PEDS screening tool divides the concerns expressed by the parent into two categories, predictive and non-predictive. Predictive means that for one concern expressed for that child, there is at least a 30% chance of future academic challenge or deficit in that area. If there are two predictive concerns expressed, then there is at least a 50% chance of future disability. Non-predictive concerns mean that concerns were expressed, but for the age of the child those concerns don't predict future difficulties.

Once parents have completed the PEDS form, the concerns are categorized and an appropriate response or path is identified for the child. The five paths (A through E) and course of action required are briefly described below:

Path A: Multiple significant concerns are expressed

- → Refer for evaluations and/or services
- Path B: One significant concern
  - Administer a second screen or refer for screening
- Path C: One or more non-significant concern
  - Brief advice, in-office counseling and informational handouts for children under 4
  - Screen behaviour and emotional well-being for children over 4 (child and family)
  - Referring for parent training or behaviour management training

Path D: Parents have difficulty communicating

→ Consider alternative detection methods

Path E: No concerns

Reassure parent that child is developing well

## **PILOT TESTING**

The questionnaire underwent a pilot testing phase with approximately 20 mothers to assess the following:

- Length
- Flow
- Comprehension

The questionnaire was revised and shortened based on the comments and expert consultations.

## **PRE-TESTING**

A pre-test was conducted at the Population Research Laboratory (PRL) in Edmonton to further assess question structure, transitional statements, additional instructions, flow of questionnaire, and length of questionnaire. The PRL worked with the Decision Support Research Team, Calgary Health Region, to refine and develop the final version of the instrument for pre-test. A total of 11 questionnaires were administered in the pre-test.

### **DATA MANAGEMENT AND ANALYSIS**

Data were obtained from the Population Research Laboratory in files for both *SPSS for Windows (version 14.0)*<sup>13</sup> and Excel. The data were then extracted to the statistical package *Stata/SE Version 9.2*<sup>14</sup> for analysis. The data were checked for missing values and inconsistencies. Data from the previous CPC study were linked by the study team to the new questionnaire data using study identification number as a key identifier.

Descriptive analyses and bivariate comparisons were conducted to assess the parental and environmental factors which were most strongly associated with development outcomes indicated by the PEDS screening tool. A chi-squared test or Fishers exact test was used where appropriate. To address the primary objective, a multivariate model was constructed using binomial regression to determine the key predictors for a high risk of developmental problems. Relative risks and 95% confidence intervals are reported.

To address the secondary objectives, three profiles of 'risk' were developed based on the literature, expert opinion and the findings from the first CPC study. These profiles included a) mothers with a history of poor mental health, b) mothers who had current poor mental health, and c) mothers with demographic risk (e.g. low income, young maternal age). Bivariate analyses were conducted to examine associations between a positive outcome on the PEDS and characteristics of children and families among mothers in each risk group. Further detail on these profiles is given in the secondary results section of this report (pp 32-34).

An alpha level of 0.05 or less was considered statistically significant for bivariate analyses and was also the cut off criteria for considering variables for regression models in conjunction with other theoretical considerations.

## **ETHICS APPROVAL**

The study received ethics approval from the Conjoint Health Research Ethics Board, Faculty of Medicine, University of Calgary. In addition, the PRL implemented a standard ethical approval process with the University of Alberta.



## Results

Results are presented in the next five sections in the following order:

- Recruitment, Participation and Geographic Distribution
- Baseline Characteristics of the Sample
- Primary Outcome of the Follow Up Study
- Characteristics of Children and Families Related to Positive Outcomes on the PEDS
- Parent Screening Preferences



## **RECRUITMENT, PARTICIPATION, AND GEOGRAPHIC DISTRIBUTION**

### **Eligibility, Recruitment, and Participation Rates**

In total, 1629 mothers from the previous CPC study were identified as potential participants for the follow up study. Attempts were made to contact 1147 mothers who had serviceable phone numbers, of which 791 were recruited and completed the questionnaire. 476 mothers were not contactable based on phone and address information from the original CPC study. Typically, the phone number was not in service or the woman was no longer was reachable at the number provided.

## Figure 1. Study flowchart mapping eligibility, recruitment, and completion of mothers who participated in the CPC follow up study



### Characteristics of Mothers who did not Participate in the Follow up Study

Compared to mothers who participated in the follow up study, mothers who were eligible to participate but did not complete the study were more likely to have the following characteristics:

- <25 years of age
- Smoker prior to and during pregnancy
- Food bank use within 12 months prior to pregnancy
- Poor network orientation during pregnancy (e.g. unwillingness to maintain, nurture or use social supports)
- Low self esteem during pregnancy

## Table 1. Characteristics of mothers who completed the follow up study compared to mothers who were eligible but did not complete the study

Characteristic	Completed N=791 n (%)	Did not complete N=356 n (%)	p-value
Maternal age <25 years during pregnancy	70 (9)	49 (14)	0.012
Marital status during pregnancy			
Married / Common law	751 (95)	328 (92)	
Divorced / Separated	10 (1)	4 (1)	0.092
Single	30 (4)	24 (7)	
Education			
Less than high school	25 (3)	20 (5)	
High school	116 (15)	56 (16)	0.110
College/university/trade/post graduate studies	648 (82)	278 (79)	
Household income per year			
< \$40,000	119 (16)	67 (20)	0.084
≥ \$40,000	635 (84)	267 (80)	0.004
Previous live births	359 (45)	168 (47)	0.570
Any smoking within 12 months prior to pregnancy	158 (20)	106 (30)	<0.001
Any smoking during pregnancy	127 (16)	83 (25)	0.001
Any alcohol within 12 months prior to pregnancy	650 (82)	280 (79)	0.159
Any alcohol during first trimester	177 (22)	92 (26)	0.221
Street drugs within 12 months prior to pregnancy	50 (6)	28 (8)	0.333
Street drugs during pregnancy	17 (2)	10 (3)	0.499
Used food bank within 12 months prior pregnancy	24 (3)	20 (6)	0.035
Poor network orientation during pregnancy			
(score cut at 30 <sup>th</sup> percentile)	226 (29)	129 (36)	0.009
Low self esteem during pregnancy			
(score cut at 30 <sup>th</sup> percentile)	179 (23)	106 (30)	0.010
Low social support during pregnancy			
(score cut at 30 <sup>th</sup> percentile)	211 (27)	103 (29)	0.435

Note: See Appendix 2 for definitions and references pertaining to Network orientation, Self-esteem, Social Support.

### **Geographic Distribution**

The map below depicts the residential location of mothers who participated in the follow up study. Mothers in the study lived throughout various parts of the city, with the majority living in the northwest and northeast parts of Calgary.

Figure 2.	Geographic distribution of CPC follow	up parti	icipants in	the city	of Calgary



Mothers who participated in the CPC follow up study lived mainly in the northwest and northeast parts of Calgary.



## **BASELINE CHARACTERISTICS**

### **Characteristics of Mothers**

The majority of mothers who participated in the follow up study had a partner, had postsecondary education, and household income over \$40,000. About 60% were currently working part or full time and almost half had been pregnant again since the CPC study. Although the majority of mothers reported good or excellent physical and emotional health, 35% self reported two or more weeks of depression after the birth of their infant.

Table 2. Characteristics of Mothers who Particip	pated in the CPC Follow Up Study
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Characteristic	N=791	%
Marital Status		
Married / Common Jaw	746	Q1 1
Divorced / Senarated / Single	140 44	56
Currently working at a naid job	482	61.2
Education	-102	01.2
Less than high school	14	18
High school	110	13.9
College/university/trade	588	74.3
Post graduate studies	79	10.0
Household income per vear		
< \$40.000	65	8.8
\$40.000-\$80.000	267	36.0
> \$80,000	410	55.3
Pregnant again since child was born	362	45.8
Moved in past 2 years	227	28.7
Any smoking in the past month	98	12.5
Any alcohol in the past month	514	65.0
Alcohol consumption 2 or more times per week in the past month	104	13.1
Anyone smoking inside the home	35	4.5
Any drugs in the past month	17	2.2
Own rating of physical health in the past 6 months		
Excellent	175	22.1
Good	424	53.7
Fair	146	18.5
Poor / Terrible	45	5.7
Own rating of emotional health in the past 6 months		
Excellent	153	19.3
Good	435	55.0
Fair	172	21.7
Poor / Terrible	31	4.0
2 weeks or more of depression post partum	281	35.5
6 months or more of depression post partum	96	12.2
Witnessed abuse since child was born	105	13.3
Mother has been abused since child was born	50	6.3
Own rating of current social support		
Excellent	438	55.4
Good	262	33.2
Fair	63	8.0
Poor / Terrible	27	3.4

### **Characteristics of Children**

The average age of the children at the time of the questionnaire was 3 years (range 18 months to 4 years), half were male, and 75% of these children had at least one sibling. Over 45% received breast milk for 6 or more months. The majority of children had a family doctor, had routine health exams, had immunization shots that were current, and were rated as having excellent or good general health by their mother. Over 85% of children were read to daily. Among those under 3 years of age, 75% spent less than 2 hours per week in structured extra-curricular activities. Among those 3 years and older, 68% spend 2 hours per week or less in structured extra-curricular activities.

Characteristic	N=791	
	mean	sd
Age (months)	38	8
	n	%
Male	383	48.4
Siblings		
0	203	25.7
1	420	53.1
2	129	16.3
3 or more	39	4.9
Birth order among siblings		
Youngest	302	51.5
Middle	65	11.1
Oldest	220	37.5
Child was breastfed for $\geq 6$ months	364	46.7
Child has regular family doctor	750	94.9
A parent stayed home with the child for ≥24 months	320	40.5
Child has had routine health exam	711	90.1
Child's immunization shots are up to date	742	94.0
Child's current general health*		
Excellent/Good	731	92.4
Fair/Poor/Terrible	60	7.6
Child received non-parental care for >20 hours per		
week in the past 6 months	481	60.8
Parent reads to child once or more per day	696	88.2
Hours spent in extra-curricular activities if child is <36 months old (N=299)		
0	134	44 8
0-2	91	30.5
25-6	47	15.7
> 6	27	9.0
Hours spent in extra-curricular activities if child is		
≥36 months old (N=492)		
O Ý	139	28.3
0 - 2	195	39.6
2.5 - 6	114	23.2
> 6	44	8.9

Table 3. Characteristics	of	Children	in th	ne Fol	low	Up	Study
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\*as rated by the child's mother

## **PRIMARY OUTCOME**

### The Parents' Evaluation of Developmental Status (PEDS)

In this sample, 11% (n=86) of children screened as being at high risk of developmental problems. From the original CPC study, there were no differences between the control, Nurse, or Nurse plus Home Visitor study groups and PEDS results. Among the 86 children who were at high risk of developmental problems, 43% had previously been referred for further testing and 57% had not been referred for further evaluation.

### Table 4. The number and proportion of children in each PEDS path

Path	Definition	n	%
A	high risk of developmental disabilities, referrals are needed	86	11%
В	moderate risk of disabilities, need for additional screening, developmental promotion, monitoring	239	30%
С	low risk of developmental disabilities but elevated risk for mental health problems, need for parent education, monitoring, and/or additional behavioural screening	186	24%
D	moderate risk of developmental disabilities, problems with parental communication and need for hands-on screening	0	0%
E	low risk for either type of disability, reassurance is the best response	280	35%

## Table 5. Mother's original CPC study group in relation to the child's outcome on the PEDS in the follow up study

	CPC Study Group				
PEDS	Control n (%) N=332	Nurse n (%) N=210	Nurse plus Home Visitor n (%) N=249	p-value	
Path A	33 (10)	19 (9)	34 (13)		
Path B	99 (30)	66 (32)	74 (30)		
Path C	82 (25)	47 (22)	57 (23)	0.737	
Path E	118 (35)	78 (37)	84 (34)		

Among the total 791 children in the study, 11% screened at high risk on the PEDS questionnaire for having developmental problems.



Figure 3. Proportion of Children in each PEDS path A, B, C, or D, and the proportion of children in Path A who were referred for further evaluation.



### **Types of Concerns**

The most commonly reported predictive concern for children in Path A and Path B was expressive language, with 81% of children in Path A and 58% of children in Path B having this concern reported by their mother. Behaviour and social-emotional concerns for the child were the most common non-predictive concerns expressed by the mother.

Type of Concern	Path A N=86 n (%)	Path B N=239 n (%)	Path C N=186 n (%)	Path E N=280 n (%)
Predictive				
Behaviour				
Global/Cognitive	10 (12)	4 (2)		
Expressive Language	70 (81)	138 (58)		
Receptive Language	36 (42)	35 (15)		
Fine Motor				
Gross Motor	20 (23)	14 (6)		
Social-Emotional				
Self Help				
School				
Other Health Issues	48 (56)	48 (20)		
Non-predictive				
Behaviour	56 (65)	120 (50)	127 (68)	
Global/Cognitive				
Expressive Language				
Receptive Language				
Fine Motor	14 (16)	12 (5)	16 (9)	
Gross Motor	5 (6)	6 (3)	8 (4)	
Social-Emotional	42 (49)	83 (35)	90 (48)	
Self Help	17 (20)	32 (13)	31 (17)	
School	25 (29)	45 (19)	34 (18)	
Other Health Issues				

Table 6. Predictive and non-	predictive concerns for	r children in	each PEDS	path
				P

### Characteristics of Children in Path A Who Had a Referral

Children in Path A who had any referrals were more likely to have been born preterm, to have had their hearing tested, or to have vision problems compared to children in Path A with no referral. Of note, preterm infants often receive additional screening and follow up as part of routine care. The smaller sample size in this group means that only large differences are likely to be statistically significant. However, it may be clinically meaningful to note that children who were not referred were more apt to have mothers who reported that their child had good or excellent health, but a greater proportion of children with a referral had their health rated as better than one year ago. In addition, a larger proportion of parents whose children were not referred scored high on hostile parenting. Demographic (e.g. income, education) and psychosocial characteristics (e.g. social support, depression) were not associated with referral.

Characteristic	Referral N=37 n (%)	No referral N=49 n (%)	p-value
Age ≥ 3 years	22 (59)	34 (61)	0.339
Born early	23 (62)	16 (32)	0.009
Male	28 (76)	32 (65)	0.300
Child has regular family doctor	34 (92)	43 (88)	0.726
Child has had routine health exam	34 (92)	46 (94)	1.000
Child's immunization shots are up to date	35 (95)	44 (90)	0.694
Child has had hearing tested	26 (70)	15 (31)	<0.001
Child has visions problems	4 (11)	0 (0)	0.031
Child's current general health*			
Excellent/Good	28 (76)	45 (92)	0.065
Fair/Poor/Terrible	9 (24)	4 (8)	0.005
Compared to 1 year ago, child's health is:			
About the same	17 (46)	32 (65)	
Better	18 (49)	16 (33)	0.191
Worse	2 (5)	1 (2)	
Child has/had congenital abnormality	2 (5)	1 (2)	0.575
Child has/had chronic breathing problems	6 (16)	4 (8)	0.249
Child has/had allergies	6 (16)	3 (6)	0.165
Child has/had eczema or psoriasis	7 (19)	14 (29)	0.302
Child has/had sleep problems	1 (3)	0 (0)	0.430
Low parenting morale	7 (19)	8 (16)	0.754
Hostile/Ineffective parenting (cut at 10 <sup>th</sup> percentile)	4 (11)	13 (27)	0.101

Table 7. Characteristics of children in Path A who had a referral compared to children in Path A who did not have a referral

\*as rated by the child's mother

Children at high risk of developmental problems that had a referral were more likely to have been born prematurely, to have had their hearing tested, and to have visions problems.

A greater proportion of mothers whose children were at high risk of problems but not referred scored high on hostile parenting.

### **Demographics, Health History, and Current Health Status**

Children who screened at high risk of developmental problems were more likely to be male, have had ear infections prior to the age of two, and to currently have their general health rated as fair, poor, or terrible compared to those at lower risk of problems. Of note, 40% of mothers with a child in Path A reported that their child's health was improved over the previous year.

	Path A	Path B	Path C	Path E	
	n (%)	n (%)	n (%)	n (%)	p-value
	N=86	N=239	N=186	N=280	
Child gender: Male	60 (70)	124 (52)	88 (23)	111 (40)	<0.001
Child has siblings	65 (76)	181 (76)	130 (70)	212 (76)	0.472
Ear infections prior to age 2	46 (53)	90 (39)	68 (37)	96 (35)	0.018
Child has problems with vision	4 (5)	8 (3)	6 (3)	8 (3)	0.846
Child was breastfed for ≥6 months	31 (36)	112 (48)	91 (49)	130 (47)	0.201
Child has/had congenital abnormality	3 (3)	9 (4)	4 (2)	9 (3)	0.820
Child has/had chronic breathing problems	10 (12)	21 (9)	15 (8)	15 (5)	0.216
Child has/had allergies	9 (11)	28 (12)	19 (10)	21 (8)	0.430
Child has/had eczema or psoriasis	21 (24)	61 (26)	47 (25)	60 (21)	0.684
Child has/had sleep problems	1 (1)	8 (3)	2 (1)	5 (2)	0.424
Child's current general health					
Excellent/Very good	73 (85)	215 (90)	177 (95 )	266 (95)	0.003
Fair/Poor/Terrible	13 (15)	24 (10)	9 (5)	14 (5)	0.003
Compared to 1 year ago, child's health is*:					
About the same	49 (57)	170 (71)	141 (76)	219 (78)	
Better	34 (40)	62 (26)	38 (20)	55 (20)	0.007
Worse	3 (3)	7 (3)	7 (4)	6 (2)	

Table 8. Child's baseline characteristics, health history, and current health status

\*as rated by the child's mother





### **Health Care**

Children who screened at high risk of developmental problems were more likely to have been referred to an early intervention program, speech and language pathologist, child developmental pediatrician, or a psychologist. These children were also more likely to have previously had their hearing tested, with many hearing tests reported as a consequence of repeat ear infections or suspected deafness.

	Path A n (%)	Path B n (%)	Path C n (%)	Path E n (%)	p-value
	N=86	N=239	N=186	N=280	-
Child has regular family doctor	77 (90)	229 (96)	178 (96)	266 (95)	0.115
Child has had routine health exam	80 (93)	219 (92)	161 (87)	251 (90)	0.178
Child has been referred to:					
Early intervention program	8 (9)	7 (3)	2 (1)	1 (1)	<0.001
Speech and language pathologist	21 (35)	30 (13)	3 (2)	6 (2)	<0.001
Child developmental pediatrician	8 (9)	7 (3)	3 (2)	4 (1)	0.005
Psychologist	3 (3)	2 (1)	0 (0)	0 (0)	0.003
Physiotherapist	7 (8)	8 (3)	3 (2)	9 (3)	0.071
Dietician	5 (6)	5 (2)	5 (3)	7 (3)	0.364
Child has had hearing tested	41 (48)	67 (28)	58 (31)	53 (19)	<0.001
Child has had hearing tested due to repeat					
or chronic ear infection	11 (27)	6 (9)	5 (9)	6 (11)	0.028
Hearing tested due to suspected deafness	15 (39)	14 (21)	6 (10)	8 (15)	0.006
Child has been to a dentist	52 (60)	122 (51)	89 (48)	151 (54)	0.238
Child's immunization shots are up to date	79 (92)	227 (95)	168 (91)	268 (96)	0.087

#### Table 9. Child's Healthcare

## Figure 4. Proportion of Children in each PEDS category who were referred to different services for additional evaluation.



35% of children who screened high on the PEDS for having a developmental problem had been referred to a speech and language pathologist.

### **Child Care**

Over 40% of the children in the study had a parent stay home with them full-time for at least the first 24 months after birth. 46% of children in the study had not received child care outside of their own parents during the previous 6 months. Among the children who did receive non-parental child care for at least 20 hours per week, there was no observed relationship between the type of day care used and the risk for developmental problems.

### Table 10. Child Care

	Path A n (%) N=86	Path B n (%) N=239	Path C n (%) N=186	Path E n (%) N=280	p-value
A parent stayed home with the child for	37 (43)	02 (38)	86 (46)	105 (38)	0 230
In the past 6 months, the child has received care from one of the following for ≥20 hours per week:	07 (40)	02 (00)			0.200
Daycare	12 (14)	36 (15)	22 (12)	36 (13)	0.787
Day nome Nannv	18 (21)	39 (16) 7 (3)	39 (21) 12 (6)	69 (25) 14 (5)	0.144 0.262
Preschool	2 (2)	9 (4)	8 (4)	9 (3)	0.865
Non-parental caregiver (i.e. friend, babysitter, relative)	23 (27)	51 (21)	45 (24)	50 (18)	0.220

### Mother's Demographics and Lifestyle

Children who screened at high risk of developmental problems or at risk of mental health problems were more likely to come from single parent families. Children who screened at high risk of developmental problems were more likely to come from families with an annual income of less than \$40,000.

### Table 11. Demographic and lifestyle characteristics of the Mother

	Path A	Path B	Path C	Path E	
	n (%)	n (%)	n (%)	n (%)	p-value
	N=86	N=239	N=186	N=280	
Marital Status					
Married/Commonlaw	79 (92)	229 (96)	173 (94)	265 (95)	
Separated/Divorced	2 (2)	6 (3)	2 (1)	12 (4)	0.014
Single	5 (6)	4 (2)	10 (5)	3 (1)	
Changed partners since child was born	1 (1)	1 (1)	8 (5)	8 (3)	0.030
Age < 25 years	2 (2)	11 (5)	13 (7)	9 (3)	0.217
Working at paid job	52 (61)	142 (59)	104 (57)	184 (66)	0.220
Education is high school or lower	18 (21)	40 (17)	28 (15)	38 (14)	0.393
Household Income per year					
<\$40,000	13 (16)	19 (8)	15 (8)	18 (7)	
\$40,000-\$80,000	35 (43)	85 (37)	68 (40)	79 (30)	0.014
>\$80,000	34 (41)	123 (54)	89 (52)	164 (63)	
Non-Caucasian plus ESL or <5 years in					
Canada	11 (13)	18 (8)	13 (7)	18 (6)	0.266
Moved 2 or more times in the last 2 years	6 (7)	10 (4)	12 (7)	11 (4)	0.463
Pregnant again since child was born	41 (48)	106 (44)	88 (47)	127 (45)	0.915
Smoked ≥1 cigarettes in the past month	17 (20)	28 (12)	24 (13)	29 (10)	0.117
4 or more drinks per occasion	3 (6)	3 (2)	4 (3)	5 (3)	0.445
Used recreational drugs in past 6 months	3 (3)	4 (2)	6 (3)	4 (1)	0.439

### Mother's Mental and Emotional health

Children who screened at a high risk of developmental problems were more likely to have a mother with a history of depression, history of witnessing someone being abused, poor network orientation during pregnancy (unwillingness to maintain, nurture or use social supports), or experience high overall distress during pregnancy.

	Path A n (%) N=86	Path B n (%) N=239	Path C n (%) N=186	Path E n (%) N=280	p-value
Rating of current physical health is fair/poor/terrible	30 (35)	61 (26)	41 (22)	59 (21)	0.058
Rating of current emotional health is fair/poor/terrible	29 (34)	62 (26)	49 (26)	63 (23)	0.217
Some tension in relationship with partner	45 (56)	92 (40)	64 (36)	92 (34)	0.004
History of depression prior to pregnancy	31 (36)	49 (20)	36 (19)	56 (20)	0.009
≥2 weeks of depression post partum	40 (47)	84 (35)	76 (41)	81 (29)	0.007
≥6 months of depression postpartum	17 (20)	27 (11)	22 (12)	30 (11)	0.150
Witnessed abuse prior to pregnancy*	46 (53)	86 (36)	76 (41)	98 (35)	0.014
History of abuse prior to pregnancy*	40 (47)	80 (33)	68 (37)	73 (26)	0.003
Witnessed abuse post partum*	18 (21)	27 (11)	23 (12)	37 (13)	0.150
Mother abused post partum*	4 (5)	12 (5)	17 (9)	17 (6)	0.348
Low social support during pregnancy	8 (9)	11 (5)	10 (5)	14 (5)	0.403
Rating of current social support is					
fair/poor/terrible	13 (15)	26 (11)	22 (12)	29 (10)	0.670
Poor network orientation during pregnancy	6 (7)	4 (2)	10 (5)	6 (2)	0.024
Feelings of distress during pregnancy	39 (45)	77 (32)	66 (35)	82 (29)	0.043
Feelings of contentment, relaxation, and					
well-being during pregnancy	43 (50)	155 (65)	139 (75)	207 (74)	<0.001

#### Table 12. Mental and Emotional Health of the Mother

\*Types of abuse could include any one of physical, emotional, sexual, financial abuse, or neglect

Note: See Appendix 2 for definitions and references pertaining to Network Orientation, Self-esteem, Social Support, distress/content.

### **Parenting**

Children who screened at a high risk of developmental problems were more likely to have a mother with low parenting morale. Mothers of high or moderate risk children were more likely to seek information about parenting from television shows.

### Table 13. Aspects of Parenting

	Path A n (%) N=86	Path B n (%) N=239	Path C n (%) N=186	Path E n (%) N=280	p-value
High Parenting Morale	71 (83)	212 (90)	166 (90)	258 (93)	0.026
Parent reads to child once or more per day	74 (86)	211 (88)	164 (89)	247(89)	0.930
Family eats 1 or more meals together daily	64 (74)	207 (87)	147 (79)	240 (86)	0.014
Attended parenting classes post partum	18 (21)	60 (25)	46 (25)	57 (20)	0.515
Attended one-time seminar/workshop on					
parenting since child was born	22 (26)	56 (23)	48 (26)	63 (23)	0.841
Watched TV shows about parenting	71 (83)	205 (86)	145 (78)	202 (72)	0.002
Read material related to parenting	83 (97)	215 (90)	176 (95)	258 (92)	0.138
Partner has attended parenting classes	7 (9)	23 (10)	20 (11)	28 (10)	0.934
Hostile/Ineffective parenting (10 <sup>th</sup> percentile)	17 (20)	30 (13)	30 (16)	36 (13)	0.302
Aversion scale (10 <sup>th</sup> percentile)	6 (7)	29 (12)	24 (13)	23 (8)	0.212

Note: See Appendix 2 for definitions and references pertaining to hostile/ineffective parenting and aversion scales.

### Key Predictors of Screening for High Risk of Developmental Problems

In this analysis, variables found to be associated with Path A on the PEDS screen were examined to determine which were the most important risk factors for predicting children who screened at a high risk of developmental problems. The outcome variable compared children at high risk of developmental problems (Path A) to children at low risk of problems (Path E). The results indicated that the following were key independent predictors:

- Maternal history of abuse or depression prior to pregnancy
- Mother's lack of contentment, relaxation, and well-being during pregnancy
- Current household income <\$40,000 per year</p>
- ♦ Male infant

## Table 14. Key predictors for scoring high risk of developmental problems on the PEDS questionnaire

Variable	Relative Risk	95% C.I.	p-value
Male infant	2.2	(1.5, 3.4)	<0.001
History of abuse or depression	1.9	(1.3, 2.7)	0.001
Lack of well-being	1.8	(1.3, 2.6)	0.001
Income <\$40,000 per year	1.4	(1.0, 2.0)	0.044

Children with mothers who had a history of abuse or depression prior to pregnancy, or had poor emotional health during pregnancy, or had a low annual income were at an increased risk of screening high for developmental problems on the PEDS questionnaire.

> Male infants had over twice the risk of screening high for developmental problems on the PEDS questionnaire compared to female infants.

## SECONDARY OUTCOMES

### Characteristics Related to Positive Outcomes on the PEDS in the Presence of Risk

In this secondary analysis, the outcome variable was subdivided to include only children who screened at a high risk of developmental problems (Path A) and children at low risk of problems (Path E) in order to compare those at highest risk to those at lowest risk. Each of the three risk profiles for the mothers were then used in three separate sub-analyses to determine characteristics related to a positive outcome on the PEDS in the presence of risk.

### MOTHERS WITH A HISTORY OF POOR MENTAL HEALTH (N=391)

Definition:

- + History of Abuse (prior to pregnancy, during pregnancy, 6-8 weeks postpartum)
- History of Depression (prior to pregnancy)
- + History of Suicidal thoughts or attempts (prior to pregnancy)
- Poor Social Support (first trimester)
- Poor Network Orientation (first trimester)
- Poor Emotional Health (first trimester)

Among mothers with a history of poor mental health, low risk of a problem as screened by the PEDS was associated with mothers who had feelings of relaxation and contentment during pregnancy and high parenting morale post partum.

## Table 15. Differences between children with a positive and negative outcome on the PEDS among mothers with a history of mental health risk

	Path A n (%)	Path E n (%)	p-value
	N=58	N=117	P
High Parenting Morale post partum	45 (77)	103 (90)	0.034
Hostile/Ineffective Parenting	48 (17)	15 (12)	0.431
Attended prenatal classes in previous pregnancy	17 (53)	47 (65)	0.240
Attended parenting classes in previous pregnancy	8 (26)	16 (22)	0.693
Partner has attended prenatal classes previously	34 (64)	77 (73)	0.272
Partner has attended parenting classes previously	4 (8)	14 (13)	0.426
Prenatal classes during pregnancy	30 (56)	52 (48)	0.345
Parenting classes during pregnancy	16 (30)	30 (28)	0.805
Ever taken a prenatal class	47 (81)	93 (82)	0.839
Ever taken a parenting class	22 (38)	41 (36)	0.833
Low distress during pregnancy	27 (47)	72 (62)	0.060
High relaxation and contentment during pregnancy	25 (43)	80 (68)	0.001
High social support during pregnancy	41 (71)	69 (59)	0.131
High network orientation	36 (62)	77 (66)	0.626

Note: See Appendix 2 for definitions and references pertaining to parenting morale, hostile/ineffective parenting, Network Orientation, distress/contentment.

### MOTHERS WITH CURRENT POOR MENTAL HEALTH (N=154)

Definition:

- Current Abuse
- Depression (6+ months post partum)
- Poor Social Support
- Poor Emotional Health

Among mothers with current poor mental health, low risk of a problem as screened by the PEDS was associated with mothers who had high parental expectations, had taken a parenting class, and had low overall distress and depression.

## Table 16. Differences between children with a positive and negative outcome on the PEDS among mothers with current poor mental health

	Path A n (%) N=23	Path E n (%) N=46	p-value
High parental expectations during pregnancy	17 (77)	40 (95)	0.042
Attended prenatal classes in previous pregnancy	6 (40)	17 (65)	0.115
Attended parenting classes in previous pregnancy	1 (7)	8 (31)	0.088
Partner has attended prenatal classes previously	11 (52)	27 (64)	0.363
Partner has attended parenting classes previously	2 (10)	7 (17)	0.705
Prenatal classes during pregnancy	12 (55)	21 (50)	0.730
Parenting classes during pregnancy	2 (9)	10 (24)	0.152
Ever taken a prenatal class	18 (78)	36 (84)	0.584
Ever taken a parenting class	6 (26)	22 (51)	0.050
Low distress during pregnancy	8 (46)	27 (59)	0.061
High relaxation and contentment during pregnancy	9 (39)	28 (61)	0.088
Low distress 6-8 weeks post partum	6 (27)	25 (61)	0.011
High relaxation and contentment 6-8 weeks post partum	3 (14)	15 (37)	0.055
High social support during pregnancy	14 (61)	24 (52)	0.494
High network orientation	9 (39)	21 (46)	0.606
Feeling blue or depressed during pregnancy	11 (50)	6 (15)	0.003
Feelings of anxiety or panic during pregnancy	11 (50)	8 (20)	0.014

Note: See Appendix 2 for definitions and references pertaining to parental expectations, hostile/ineffective parenting, network orientation, distress/contentment, social support.





### MOTHERS WITH CURRENT DEMOGRAPHIC RISK (N=129)

Definition:

- <25 years old
- High school education
- \$40,000 annual income
- ♦ Single
- Moved 2 or more times in the past 2 years

Among mothers with demographic risk characteristics, low risk of a developmental problem as screened by the PEDS was associated with mothers who had taken a prenatal class, had low overall distress and feelings of relaxation and contentment during pregnancy, or had high parenting morale.

## Table 17. Differences between children with a positive and negative outcome on the PEDS among mothers with demographic risk

	Path A	Path E	
	n (%)	n (%)	p-value
	N=20	N=37	
High Parenting Morale post partum	12 (60)	32 (86)	0.023
Hostile/Ineffective Parenting	5 (25)	5 (14)	0.277
Prenatal classes during pregnancy	7 (41)	14 (41)	0.100
Parenting classes during pregnancy	2 (12)	5 (15)	0.774
Ever taken a prenatal class	9 (45)	26 (74)	0.030
Ever taken a parenting class	4 (20)	14 (40)	0.128
Low distress during pregnancy	6 (30)	26 (70)	0.003
High relaxation and contentment during pregnancy	9 (45)	27 (73)	0.037
High social support during pregnancy	11 (55)	23 (62)	0.599
High network orientation	11 (55)	21 (57)	0.898

Note: See Appendix 2 for definitions and references pertaining to parenting morale, hostile/ineffective parenting, network orientation, social support, distress/contentment.





### **Parent Screening Preferences**

Mothers were asked about how and where they would prefer screening to be completed. About 50% of the mothers indicated that they preferred a face-to-face interview format, and 43% indicated they would prefer the setting to be their doctor's office.

Table 18. Screening preferences for completing the PEDS questionnaire

	n	%
Format of screening questionnaire		
Computer	190	24
Written questionnaire	111	14
Interview	385	49
No preference/Other	104	13
Location of screening		
Community health centre	207	26
Doctor's office	340	43
No preference/Other	242	31





## Conclusions

Although most children in this follow up study were healthy and meeting developmental milestones, more than half of the children who screened at high risk for developmental problems had not been previously identified or referred for further assessment. The characteristics of children and families more likely to screen at high risk for developmental problems by the PEDS included male infants, infants with ear infections prior to the age of two years, infants from families with a low income or single parents, infants with mothers who had a history of poor mental and emotional health, and infants with mothers who had low parenting morale. There is an opportunity to better understand the relationship between risk factors and outcomes, and, as importantly, to identify families and children at higher risk for developmental problems in order that appropriate services and support be provided to encourage optimal child development.

Parents rely on primary health care providers for physical and developmental assessment of their infants and preschool children. Primary care providers have identified significant barriers to the implementation of universal developmental screening, including the time involved, limited reimbursement for screening efforts, and their perception that existing measures or parent concerns are inaccurate or unreliable, especially when a child is very young<sup>3, 4</sup>. The implementation of a quick, simple and effective screening tool has the potential to greatly improve the early detection of developmental problems, with the potential for earlier intervention and improved long term outcomes for children.

### **Key Points**

- 1. Of those mothers who participated in the follow up study, the majority were married with household incomes in excess of \$40,000 per year. A total of 40% of mothers reported that a parent stayed home full time until the child was at least 2 years old, and over 45% reported providing breast milk for at least 6 months. Currently, 60% were working part or full time at a paid job and almost half of the mothers had been pregnant again since the CPC study. Although the majority of mothers reported their current physical and emotional health as good to excellent, 35% self reported two or more weeks of depression after the birth of their infant.
- 2. The majority of pre-school children were spending less than 2 hours per week in structured extra-curricular activity, and almost 90% of children were read to at least daily.
- 3. Using the PEDS, 11% of children screened at high risk of developmental problems. Among these 86 children, 43% had been referred for services. Thirty percent of children screened at moderate risk of developmental problems, 24% at risk of mental health concerns and 35% screened at low risk of concern.
- 4. Children who screened at high risk for developmental problems (PEDS Path A) who had been referred to services or follow up were more likely to have been born preterm (<37 weeks completed gestation), to have had their hearing tested, and to have vision problems compared to children who screened at high risk of problems who had not been previously referred. The primary referral was to a speech and language pathologist.

- 5. Male children were identified as having twice the risk of developmental problems. Additional factors that increased the risk of developmental problems by 40% to 90% included children born to mothers who had a history of abuse or depression prior to pregnancy, who experienced distress and lack of well-being during pregnancy or who lived in homes with a household income <\$40,000 per year.</p>
- 6. Among those mothers with past poor emotional health, current poor emotional health, or demographic risk, factors that in general distinguished families of children at low risk of developmental problems from those with high risk of problems included: positive feelings during pregnancy, lower overall distress during pregnancy, higher parent morale post partum, and having attended a parenting class.
- 7. The majority (over 80%) of mothers were obtaining parenting information from the television, with less than 25% reporting attendance at parenting classes or seminars.
- 8. Mothers indicated that their first choice for screening venue would be at a physician's office. They would prefer that screening was conducted by a face-to-face interview.

## Recommendations

- 1. Telephone follow up to screen for developmental problems using existing physician or hospital data bases is apt to miss children who live with younger mothers who smoke, use food banks, or have low self esteem. This analysis suggests that these mothers are also at higher risk of having a child with developmental problems.
- 2. Children at high risk for problems who are not born preterm are at risk of underidentification. However, over 90% of these children are seen for routine check ups and immunization. These routine check ups and immunizations visits may be missed opportunities for regular and repeated developmental screening in settings where mothers already take their children. Routine screening as a component of well child immunization visits warrants serious consideration.
- 3. Demographic and mental health characteristics of mothers whose children are at high risk of problems may be identifiable during pregnancy and prior to delivery (e.g. histories of abuse, distress, and depression). There is an opportunity to develop programs that improve the health and well being of mothers which ultimately may have a positive impact on child development. Such programs could begin in the prenatal period and continue through early childhood and be designed to address self esteem, the ability to seek and obtain help, parenting skills and morale.
- 4. Among women with mental health and demographic risks, those who had feelings of relaxation and contentment during pregnancy, who had lower overall distress and higher parenting morale were less likely to have a child who screened at high risk of developmental problems suggesting that efforts to improve emotional health and well being prior to delivery may reduce the likelihood of adverse developmental outcomes. Furthermore, those women who had attended a parenting class were less likely to have a child who screened at high risk for problems, suggesting that efforts to enable women to obtain information about pregnancy and parenting may be important to enhance optimal child development.
- 5. Given the high proportion of parents who indicate they obtain parenting information from television, this medium should be considered for the delivery of evidence-based information on parenting and child development.
- 6. The feasibility of routine developmental screening in a primary care setting should be pilot tested. In addition, methods to complete screening instruments (face-to-face interview with physician versus parent-completed screen) should be explored.
- 7. Preliminary results suggest that 41% of children would benefit from further assessment of development (11% at high risk and 30% at moderate risk), while 24% of mothers may require additional support to address mental health and behavioural issues. Routine/universal screening would require appropriate downstream support for children and families prior to implementation. The World Health Organization has guidelines to aid with decision making in this regard.

## **Appendices**

## APPENDIX 1: CPC STUDY METHODS

### Design

This CPC study was a prospective randomized controlled trial that involved women attending three family physician low risk maternity practices in the Calgary Health Region:

City Region	Clinics	Clientele
Northwest (NW) Calgary	Low Risk Maternity Clinic Grace Maternal Child Clinic	On average, these clinics tended to serve a primarily English speaking, middle to upper socioeconomic clientele.
Northeast (NE) Calgary	Maternity Care Clinic	On average, this clinic tended to serve a more ethnically and economically diverse population.

Women were recruited into the study prior to their first appointment at the prenatal clinics and after informed consent. 2015 women (1015 from the NW clinic and 1000 from the NE clinic) completed a baseline study questionnaire and were randomly assigned to receive one of the following:

Control group: current standard of care at the prenatal clinics

**Nurse Intervention Group:** standard of care plus consultation with a Nurse trained to provide prenatal support

**Nurse plus Home Visitor Intervention Group:** standard of care plus consultation with a Nurse plus consultation with a Home Visitor (HV) trained to provide non-medical prenatal support

Of the 2015 participants, 278 women were recruited during a pre-study phase to determine if physician practice would change as a result of introducing the trial into their clinics.

### Recruitment

The study took place between April 2001 to July 2004. Contact information for all women booked into the prenatal clinics was provided to a Research Assistant and entered into a Computer Assisted Telephone Interviewing (CATI) System. Trained telephone interviewers contacted patients, provided information about the study, and invited patients to participate. Receptionists and Office Managers at the clinics were asked to inform new patients about the study, and referring physicians were asked to post information about the study at their offices.

Recruitment in the study was voluntary. Patients who did not participate received the standard of care (plan agreed upon by the women/family and her/their physician).

### **Exclusion Criteria**

Patients were excluded from the study if they:

- × were under 18 years of age (due to ethical issues related to informed consent)
- ► had their first appointment with the prenatal clinic prior to completing the baseline study questionnaire
- × did not plan to attend the clinic at the time of the first recruitment call
- ▼ lived outside the Calgary Health Region
- were not pregnant (e.g. abortion, miscarriage) at time of contact for recruitment could not communicate to study interviewers or translators in either English, French, Cantonese, Mandarin, Punjubi / Urdu / Hindi, or Arabic dialects.

### **Data Collection**

Three questionnaires were developed based on input from focus groups and consultations with physicians, nurses, epidemiologists, program developers, psychologists, and published literature. Other than the standardized tools referenced in this report, additional sources for the CPC study questionnaires included the National Population Health Survey, National Longitudinal Survey of Children and Youth, Canadian Perinatal Nutrition Program, and the Pregnancy Risk Assessment Monitoring System (PRAMS). As required, questions were created when previous tools were not available.

Interviewers were trained specifically to each of the three questionnaires and were provided with glossaries and response guides. Interviewers were also supervised. Data quality was monitored by periodic review of questionnaires for completeness. All study interviews in the English language were conducted on the CATI system. The interviews were also translated into French, Cantonese, Mandarin, Punjabi / Urdu / Hindi, and Arabic dialects. Translated interviews were completed in paper format and then entered on the CATI system.

### **Components of the Interviews**

### **Baseline Telephone Interview**

Prior to the first appointment at the prenatal clinics and randomization, a baseline telephone interview (approximately 45-60 minutes in duration) was conducted with women who agreed to participate to determine:

- Verbal consent for baseline interview
- **×** Baseline demographics
- Current and previous obstetrical history
- ► Lifestyle, including diet, exercise, smoking, alcohol use, street drug use (currently, during the previous year and during previous pregnancies)
- ▼ Food security
- ▼ Height and weight
- **×** Symptoms, thoughts, feelings, and experiences including:
  - Symptom Questionnaire (Kellner)<sup>15</sup>, an instrument that measures depression, anxiety, somatization, anger-hostility, contentment, relaxation, friendliness, and somatic well-being
  - Rosenberg Self Esteem Scale<sup>16</sup>
  - Abuse (victim or witness of abuse) (Woman Abuse Screening Tool)<sup>17</sup>
  - History of stressful life events
  - Network Orientation Scale<sup>18</sup>
  - Social Support Index<sup>19</sup>
- ▼ Housing environment

### The Community Perinatal Care Follow Up Study

- ➤ Details about spouse/partner/baby's father (e.g. support, lifestyle, relationship)
- Community and social support
- ➤ At the baseline interview, interviewers also confirmed that participants were aware of the regional pregnancy guide "From Here Through Maternity" and were encouraged to talk to their family doctors if they had any questions or medical concerns during the study.

### **Mid-Pregnancy Telephone Interview**

At 30-32 weeks gestation, participants completed a second telephone interview (approximately 25-45 minutes in duration) to determine:

- × Pregnancy status and prenatal contacts
- × Expectations about delivery, infant care, and parenting
- × Lifestyle during pregnancy (alcohol use, smoking, street drugs, diet, exercise)
- ▼ Food security
- × Symptoms, thoughts, feelings, and experiences including:
  - Feelings about pregnancy
  - Symptom Questionnaire (Kellner)<sup>15</sup>
  - Rosenberg Self Esteem Scale<sup>16</sup>
  - Abuse (victim or witness of abuse) during pregnancy (Women Abuse Screening Tool)<sup>17</sup>
- ▼ Housing environment
- ➤ Details about spouse/partner/baby's father (e.g. support, lifestyle, relationship)
- × Updated demographics and work/occupation experiences and stressors

### **Eight Week Post Partum Telephone Interview**

At 8 weeks post partum, participants completed a final telephone interview (approximately 40-60 minutes in duration) to determine:

- × Infant outcomes, details about labour and delivery, and initial hospitalization
- ▼ Re-hospitalizations
- Pregnancy complications
- Pregnancy resources/contacts/support
- Resources/contacts/support since delivery
- Prenatal care (topics discussed with caregivers, satisfaction with caregivers, satisfaction and feedback on CPC Nurse or Home Visitor if applicable)
- Infant feeding/care and maternal confidence
- ✗ Lifestyle (post partum)
- ▼ Food security (post partum)
- × Symptoms, thoughts, feelings, and experiences (post partum) including:
  - Symptom Questionnaire (Kellner)<sup>15</sup>
  - Rosenberg Self Esteem Scale<sup>16</sup>
  - Edinburgh Postnatal Depression Scale<sup>20</sup>
  - Post partum abuse (Women Abuse Screening Tool)<sup>17</sup>
- ▼ Housing environment
- ➤ Details about spouse/partner/baby's father (e.g. support, lifestyle, relationship)
- × Child care, social support, and practical social support
- × Updated demographics and work/occupational status

### **Pilot Testing**

The questionnaires were developed by the project team with input from physicians at the prenatal practices, a senior epidemiologist, other clinical experts including psychologists and Master's prepared nurses, as well as community program experts and leaders. The questionnaires were then pilot tested on 20 women from the prenatal clinics to obtain their feedback. Questionnaires were revised to address unclear wording.

### Randomization

Prior to the start of the study, a random assignment list was generated in Microsoft Access using a Sequential Blocked Randomization technique. The details of this process were as follows:

- 1. Sample sizes of 900 participants from the NE Clinic and 900 from the two NW clinics were predetermined. In general, the sample size was calculated to be large enough to allow for multivariate analysis and to detect a 5% change in resource use as statistically significant.
- 2. Within each quadrant (NE or NW Calgary), random assignment to the three study groups was generated using 10 blocked sequences of 90 records. Using this method, assignment to the study groups would be evenly distributed every 90 participants until 900 participants per quadrant were randomized.
- 3. Once compiled, the random list of assignment was stored in a secured database accessible only to the Study Coordinator and Research Assistant.

### **Assignment to Study Groups**

Each week during the reference period, the Study Coordinator and/or Research Assistant extracted a list of completed interviews from the study databases. Women who had completed the baseline interview were assigned to the predetermined randomization list in ascending order according to the date and time at which they completed the baseline interview.

### **Notification of Random Assignment and Consent Forms**

After random assignment, participants were notified which study group they were in. Patients who were randomized to consult with the Nurse or Home Visitor completed a consent form at their first appointment. Patients who were randomized to the Control group were requested to return the consent form by mail in a pre-stamped and addressed envelope.

### **Disclosure of Random Assignment**

The nature of the intervention made a double-blinded design impossible. As noted above, patients were notified about the study group to which they were assigned, and this information would be readily apparent when consulting with the Nurse or Home Visitor. The Nurse was also notified which patients were assigned to see them and/or the Home Visitor. Communication sheets were created so that Nurses could highlight important issues to the physician, as would ultimately occur in a clinical practice. The clinics were not notified which patients were in the control group, were ineligible, or refused to be in the study.

## **APPENDIX 2: STANDARDIZED INSTRUMENTS**

### Standardized Instruments used in the CPC Study

### Kellner Symptom Questionnaire<sup>15</sup>

The Kellner Symptom Questionnaire (SQ) is a self-rated scale that measures distress and wellbeing. The patient is instructed to read quickly through a list of 92 psychiatric and somatic conditions and choose the response (yes or no, true or false) that best describes how she has been feeling during the past week and on the day of the interview. Respondents are given a rating of one for each symptom that is checked "yes" or "true" and for each statement of wellbeing that is checked "no" or "false." A higher score indicates more distress than a lower score. The SQ has good reliability and validity. Specifically, the test-retest reliability of the SQ was determined in a study of 18 anxious outpatients at four weeks. The test-retest correlations for the subscales were; anxiety 0.71; depression 0.95; somatic 0.77; hostility 0.82. The SQ has been validated against the Hamilton Depression and Anxiety Rating Scales. The correlation of the SQ depression scale with the Hamilton Rating Scale for Depression was 0.66 in a depressed population and 0.65 in a matched normal control group. The correlation of the SQ anxiety scale with the Hamilton Anxiety Rating Scale was 0.69.

### Rosenberg Self Esteem Scale<sup>16</sup>

The Rosenberg Self Esteem Scale (SES) measures positive or negative orientation toward oneself. It provides an overall evaluation of ones worth or value. The SES is the most widely used self esteem measure in social science research. The scale contains 10 items, some of which are reverse-coded prior to scoring. The answer choices range from "strongly agree" to "strongly disagree." The scores range from 0-30, with 30 indicating the highest score possible and highest rating of self esteem.

### Network Orientation Scale<sup>18</sup>

The Network Orientation Scale (NOS) is a 20-item self report scale used to assess negative network orientation which is the perspective that it is inadvisable, useless, or risky to seek help from others. The NOS does not measure whether a person has adequate social support, but instead is used to determine if the individual is willing to utilize, maintain and nurture their supports. Each question is rated on a scale of agreement from one "strongly agree" to four "strongly disagree". A total score ranging from 20 to 160 is obtained, with higher scores indicating more negative network orientation. The Cronbach's alphas, measuring interval consistency of the NOS range from 0.60 to 0.88. Test-retest correlations were 0.85 and 0.87 over one and two week intervals respectively.

### Social Support Index<sup>19</sup>

The Social Support Index (SSI) is a 17 question self-report questionnaire designed to assess how the family views the community as a source of support. Each question is rated on a five point scale of agreement ranging from zero "strongly disagree" to four "strongly agree". A total score is obtained by summing up all scores. A minimum of 0 and a maximum of 68 are possible. The internal consistency of the SSI, measured by Cronbach's alpha is 0.82. The testretest correlation is 0.83.

### Edinburgh Postnatal Depression Scale<sup>20</sup>

The Edinburgh Postnatal Depression Scale (EPDS) is a ten item self-report questionnaire. Responses are scored from zero to three, for a maximum score of 30. The EPDS was designed specifically for postpartum women and therefore does not include questions about changes in sleep and energy, which are normal symptoms of the postpartum period. The EPDS has been shown to have good reliability and validity. In a community sample of 60 postpartum women with major or minor depression, the internal consistency of the EPDS was 0.87. The validity of the EPDS was determined in a cohort of 84 new mothers, including women with depressive illness and controls, using a cut point of 12 or greater. The sensitivity of the EPDS for identifying women with major or minor depression as diagnosed according to the Research Diagnostic Criteria (RDC) was found to be 86% while the specificity was 78%. The positive predictive value for identifying women who met RDC criteria was 73%.

### Parental Expectations Survey<sup>21</sup>

The Parental Expectations Survey (PES) is used to assess new parents perceptions about their abilities to take care of their new infants. The PES was also modified to create a prenatal version after permission was granted from the author specifically for the CPC study. Both instruments have 25 self report items. Each question is rated on a Likert-type scale scored from zero (cannot do) to ten (certain can do). The average score from the questionnaire is obtained by summing all scores and dividing by the total number of scores. The psychometric testing of the PES was completed on a sample of 82 first-time mothers. The Cronbach's alpha was 0.91 at one month postpartum and 0.86 at three months postpartum. Concurrent validity was determined by comparing the women's scores on the PES to the women's scores from Self-Evaluation subscale of the "What Being the Parent of a Baby is Like" Questionnaire (WPL-R). Correlations of 0.75 at one month postpartum and 0.64 at three months postpartum were found between the two scales.

### Standardized Instruments Used in the CPC Follow Up Study

### Parents' Evaluation of Developmental Status<sup>2</sup>

The Parents' Evaluation of Developmental Status (PEDS) is an evidence-based 10 item parent report screening measure designed to facilitate parent-professional communication about development and to ensure that development and behaviour problems in children birth to 8 years of age are detected and addressed. This is done by eliciting parent concerns, determining children's level of risk for disabilities, and identifying the optimal professional response. The PEDS screening tool divides the concerns expressed by the parent into two categories, predictive and non-predictive. Predictive means that for one concern expressed for that child, there is at least a 30% chance of future academic challenge or deficit in that area. If there are two predictive concerns mean that concerns were expressed, but for the age of the child those concerns don't predict future difficulties. The PEDS has high inter-rater reliability for both categorization of concerns (0.95) and for the elicitation of virtually identical sets of concerns by different examiners (0.88). The test-retest reliability is 0.88 and the internal consistency is 0.81.

### Parenting Morale Index<sup>11</sup>

The Parenting Morale Index (PMI) is used as a measure of parent morale or positive spirits. The 10 items reflect a range of hedonic tone, and seek to assess frequency of distinct affect states rather than their intensity. Each item is measured on a likert scale, with some items being coded in reverse prior to summing the total score. An alpha coefficient of 0.84 was found for the total PMI score. These findings were consistent when factor analyses were conducted separately for mothers and fathers.

### National Longitudinal Survey of Children and Youth (NLSCY)<sup>12</sup>

The Hostile Parenting scale from the NLSCY is a 7 item measure adapted from Parenting Practice Scales designed to measure the frequency that the parent gets annoyed with the child for disobedience, offers little praise, uses high levels of disapproval when talking to the child, gets angry when punishing the child, punishment depends on parent's mood, and disciplines repeatedly for the same thing. The theoretical range varies with number of items at each age. A higher score indicates more hostile/ineffective parenting practices. The Cronbach's alpha is 0.70. The top 10th percentile was used to indicate scores the problematic range.

The Aversion Parenting scale is a 7 item measure written specifically for the NLSCY by Dr. M. Boyle, McMaster University. The scale was designed to measure aversive/non-aversive discipline techniques. Items include strategies to manage child misbehaviour such as, "Raise you voice, scold or yell at him/her" and "Use physical punishment." The theoretical range of items is 7 to 35 and a higher score indicates more aversive discipline practices. The Cronbach's alpha is 0.57. The top 10th percentile was used to indicate scores the problematic range.

## References

- Tough SC, Johnston DW, Siever J. Community Perinatal Care Study. Calgary, AB: Prepared for the Calgary Children's Initiative (United Way) and the Calgary Health Region; 2005.
- (2) Glascoe FP. PEDS: Parents' Evaluation of Developmental Status. *www forepath org* 2005;Available at: URL: <u>www.pedstest.com</u>. AccessedJuly, 2005.
- (3) Rydz D, Shevell MI, Majnemer A, Oskoui M. Developmental screening. *Journal of Child Neurology* 2005;20:4-21.
- (4) Sices L, Feudtner C, McLaughlin J, Drotar D, Williams M. How do primary care physicians identify young children with developmental delays? A national survey. *Journal* of Developmental & Behavioral Pediatrics 2003;24:409-17.
- (5) Dawe U. Regional Programs: Maternal-Newborn: Final Report of the Program Design Committee. Prepared for the Calgary Health Region; 1997.
- (6) Committee on Children With Disabilities. Developmental Surveillance and Screening of Infants and Young Children. *Pediatrics* 2001;108:192-5.
- (7) Williams J, Holmes CA. Improving the early detection of children with subtle developmental problems. *Journal of Child Health Care* 2004;8:34-46.
- (8) Glascoe FP. A method for deciding how to respond to parents' concerns about development and behavior. *Ambulatory Child Health* 1999;5:197-208.
- (9) Mentore JL. The effectiveness of early intervention with young children "at risk": A decade in review 2000.
- (10) Talay-Ongan A. Early intervention: Critical roles of early childhood service providers. International Journal of Early Years Education 2001;9:221-8.
- (11) Trute B, Hiebert-Murphy D. Predicting family adjustment and parenting stress in childhood disability services using brief assessment tools. *Journal of Intellectual & Developmental Disability* 2005;30:217-25.
- (12) Strayhorn JM, Weidman CS. A Parent Practices Scale and its relation to parent and child mental health. *Journal of the American Academy of Child & Adolescent Psychiatry*.
- (13) SPSS for Windows, Version 14.0 [computer program]. Version 14.0. Chicago, IL: SPSS Inc.; 2005.
- (14) Stata Statistical Software: Release 9 [computer program]. Version 9.0. College Station, TX: StataCorp LP; 2005.
- (15) Kellner R. A symptom questionnaire. *J Clin Psychol* 1987;48:268-74.
- (16) Rosenberg MJ. Society and the Adolescent Self-Image. Revised ed. Middletown, CT: Wesleyan University Press; 1989.

- (17) Brown JB, Lent B, Brett PJ, Sas G, Pederson L. Development of woman abuse screening tool for use in family practice. *Fam Med* 1996;28:422-8.
- (18) Vaux AC, Burda PC, Stewart D. Orientation toward utilization of support resources. *J Community Psychol* 1986;14:159-70.
- (19) McCubbin HI, Patterson J, Glynn T. Social support index (SSI) (1982). In: Corcoran K, Fischer J, editors. *Measures for Clinical Practice: A Sourcebook*. 3 ed. New York: Free Press; 2000. p. 446-7.
- (20) Cox JL, Holden JM, Sagovsky R. Detection of postnatal depression: development of the 10-item Edinburgh Postnatal Depression Scale. *Br J Psychiatry* 1987;150:782-6.
- (21) Reece S. The parental expectations survey: a measure of perceived self-efficacy. *Clinical Nursing Research* 1992;1:336-46.