Health PEI

Children with Complex Needs Survey

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Executive Summary

Introduction

Children with complex needs have, or are at increased risk for chronic physical, developmental, behavioral or emotional conditions. Multiple services in several health settings are required to address their needs, which have a functional impact beyond that experienced by children generally. Coordination of the required services for a child with complex needs can also be challenging.

The objective of the Health PEI Children with complex needs survey is to determine:

- 1) An estimate of the number of children and youth in PEI who have complex health care needs or health care needs that could become complex.
- 2) How many of these children and youth have unmet needs?
- 3) Would caregivers use a service to assist with access and coordination if available?

With a better understanding of the magnitude of the children with complex needs population and their potential needs, Health PEI aims to develop and improve programs for children with complex needs and all children accessing health care services.

Methodology

Caregivers of children and youth under the age of 18 were asked to fill out one Health PEI children with complex needs survey for each child/youth they care for, regardless of the health status of the child/youth. The survey was administered from June 5 to September 19, 2021.

Weighting was applied to the survey samples to reflect a more accurate distribution of the PEI population, in order to obtain population-based estimates.

To qualify as children with complex needs, the following two criteria must be met:

- 1) Children experience a functional limitation due to a physical, developmental, behavioral or emotional condition, and the condition has lasted or is expected to last for at least 12 months <u>and</u>;
- 2) Children have <u>at least two</u> of the three health consequences in the survey that are due to a physical, developmental, behavioral or emotional condition, and the condition has lasted or is expected to last for at least 12 months

Complexity was stratified into four levels using combinations of both the number of areas of health care needs, and the number of service areas with access difficulties.

Results

- A total of 1,860 completed responses were collected, which account for 6.2% of the total target population.
- Based on the weighted survey results and population data, it could be estimated that there are about 5173 children with complex needs in PEI. This would account for about 17.3% of PEI children under the age of 18 having complex needs.
- About 84% of PEI children with complex needs have experienced difficulties accessing required health services in the past 12 months.
- Almost all (97%) of the caregivers of children with complex needs expressed interest in services that would help them find and organize care for their children.

Conclusion

Children with complex needs are a relatively small population yet one that tends to use the health care system extensively. They are at risk of having unmet needs due to access difficulties, financial constraints, and fragmented services. An estimated 5173 children and youth in the province of PEI are considered at risk for complex needs with extensive difficulties in accessing services (84 % at least one service). Almost all of the care givers of the identified children with complex needs (97%) expressed a desire for additional support in finding and organizing their care. The next step in this project will be to submit a business case for a Navigator position in order to complete the development of and then implement a coordination program.

Further investigation into access difficulties in all areas is needed, with mental health services for children and youth being a priority.

Limitations

- Results were weighted due to a disproportional response rate from caregivers of children in the 5-12 year old category compared to the much lower 0-4 category responses. Responses were also disproportionate by region with Kings County respondents being much fewer than Queens and Prince counties.
- Survey tool: The survey was based on a validated tool with several differences. A focus group
 assessed the comprehensibility of the Survey, but its validity and reliability were not formally
 evaluated. The name of this survey has also been suggested to disproportionally target caregivers of
 children with complex needs.
- Scoring system: The survey was used to determine how many children under 18 years of age on PEI
 met the Steering Committee criteria for CwCN. These criteria seek to identify those most in need of
 navigation or coordination services. The criteria used in this survey may turn out to be too broad or
 restrictive in scope and require revision. Future work will be needed to determine feasible scope of a
 navigation/care coordination program.
- COVID: The Survey was administered during the COVID -19 Pandemic which may have skewed results a concern noted by multiple other surveys world-wide.
- Comparing populations: Although the number of respondents was sufficient to reliably estimate the provincial population of CwCN on PEI, comparing sub-populations was not possible at this time.

Next Steps

- 1) Using the current data set, we propose to further describe respondents with 2 or 3 Health Consequences who did not meet Functional Limitations criteria.
- 2) Further improve and validate the Survey for future use in identifying CwCN and potentially as an outcomes tool, particularly if sufficient numbers of CwCN respond. Such work, while difficult and time consuming, may be of value in evaluating a potential navigation / coordination service.
- 3) Use the current survey data to further develop a Navigation/care coordination program proposal

Children with Complex Needs Complete survey

Introduction

Studies in Canada, the United States, and throughout the world suggest that approximately 20% of children have or are at increased risk for chronic physical, developmental, behavioral, or emotional conditions and require health and related services of a type or amount beyond that required by children generally (1, 2). The relatively small population of children with complex needs requires a disproportionate number and intensity

of health care services. Accessing and coordinating required services for this population poses major challenges to caregivers and healthcare providers alike. Recognizing these challenges, Health PEI established a Children with Complex Needs (CwCN) Steering Committee in 2012 to address access to and coordination of care for this population.

Early work by the Committee identified potential approaches for improving healthcare delivery and coordination in specific areas (e.g. nutrition, speech language pathology) of high need in PEI. Recognizing that many challenges are similar regardless of specific needs or services, the Committee has spent the past 5 years focusing more on ways to improve healthcare delivery and coordination of care for CwCN without regard to specific underlying conditions. To aid this process, Davis Pier Consulting was hired to complete a business process redesign through a partnership with Information Technology Shared Services (ITSS). Davis Pier assisted the Steering Committee in establishing a working definition of the population, identifying key strategies for improving access to services and coordination of care, and measuring and tracking outcomes of potential interventions. During this process, several questions became apparent including:

- 1) How many CwCN are there on PEI?
- 2) How many have unmet needs?
- 3) Would caregivers use a service to assist with access and coordination if available?

A Survey was developed to answer these questions and also potentially identify the most prevalent healthcare conditions affecting CwCN in PEI. The Survey was made available in English and French (see appendix 1) between June 5 and Sept 19, 2021. While the <u>target population was all children in PEI under 18 years of age</u>, responses were solicited from caregivers of this population, predominantly parents. A total of 1860 completed Surveys were included in the analysis representing 6.2% of the under 18-year-old population on PEI.

Of the respondents, 17.3% met the Committee's working definition of CwCN which included both:

A functional limitation due to a physical, developmental, behavioral or emotional condition that has lasted or is expected to last for at least 12 months

AND

<u>At least two</u> of the following three health consequences due to a physical, developmental, behavioral or emotional condition that has lasted or is expected to last for at least 12 months:

- Use or need for prescribed medicine or supplements
- Frequent or ongoing use or need for medical care, mental health services or extra educational supports
- Use or need for therapies

Looking at the CwCN population alone, their Caregivers reported that 84% had at least 1 unmet need and 65% had at least 2 unmet needs related to their health consequences. Furthermore, 96.8% said they would use a service to help them find and organize care if it were available.

In relation to the current population of children and youth in PEI, the survey results would suggest that approximately 5174 children and youth under 18 years of age on PEI meet the Steering Committee working definition for CwCN. Many have trouble accessing needed care or services, and almost all caregivers would seek assistance with access to and coordination of care if a service were available. Details of the Survey methodology, analysis, results, and conclusions as well as limitations, further analyses to be completed and potential next steps follow.

Survey Methodology

Target Population

While the target population of this survey was all PEI children and youth under the age of 18, their caregivers, predominantly parents, were the targeted survey respondents on behalf of the children. Caregivers were asked to fill out one survey per child/youth for each child/youth they care for regardless of their health status.

Data Collection

The Survey was available online and in paper form in both English and French for completion from June 5 to September 19, 2021. Responses were self-reported by caregivers and completely anonymous.

Responses were solicited using a variety of strategies including mass communication designed to raise general awareness such as:

- Social medias of PEI government, departments, and partner organizations
- Websites and newsletters of various partner organizations and departments
- TV interview on CBC Compass evening news
- Posters in offices of public health programs

and by working with partners involved with different age and/or other groups (Table 1).

Table 1. Targeted Survey Invitations

able 1. Targeted Survey invitations					
Age Group of Target Population	Partner Department / Organization / Program	Method of Survey Distribution			
() - 17 I (Public Health Nursing Pediatricians Pediatric		Many clinicians introduced the survey to parents during appointments.			
1 - 4	Early Childhood Development	Some early learning centres sent the survey link to parents via email.			
5 - 17	Public Schools Branch (PSB) La Commission Scolaire de Langue Francaise (CSLF)	Principals of all schools sent the survey invitation to all student households.			

Lennox Island First Nations
PEERS Alliance
Autism Society of PEI
Immigrant & Refugee Services Association PEI (IRSA)
PEI Association for Community Living (PEIACL)

All organizations sent the survey link to clients via email and introduced the survey to clients in appointments as appropriate.

Instrument Development

0 - 17

The Health PEI Children with Complex Needs (CwCN) Survey was based in part on the Children and Youth with Special Health Care Needs (CYSHCN) Screener (Appendix 2). This validated tool has been widely used to estimate the number of "children and youth who have or are at increased risk for chronic physical, developmental, behavioral, or emotional conditions and require health and related services of a type or amount beyond that required by children generally" in the US and elsewhere (2). Permission to use the CYSHCN Screener in developing the CwCN Survey was granted by the Child and Adolescent Health Measurement Initiative in response to a formal request by the Health PEI Provincial Children with Complex Needs Coordinator.

Survey Questions and Scoring

The CwCN Survey uses non-condition specific, consequences-based criteria. It consists of six questions related to personal demographic information and six core questions, four of which have sub-questions (Appendix 1). Responses to the core questions are reported individually and also in combination to identify children and youth under age 18 meeting the Steering Committee's working definition for CwCN. The working definition was developed using the work done by Children's Healthcare Canada in the CAPHC National Complex Care Guidelines (3), work being done by the IWK Hospital in Halifax, and other definitions in the literature (4). The CwCN Criteria used include:

1) A functional limitation due to a physical, developmental, behavioral or emotional condition that has lasted or is expected to last for at least 12 months (Survey Question 3, 3a, 3b)

AND

- 2) At least two of the following three health consequences due to a physical, developmental, behavioral or emotional condition that has lasted or is expected to last for at least 12 months:
 - A) Use or need for prescribed medicine or supplements (Survey Questions 1, 1a, 1b)
 - B) Frequent or ongoing use or need for medical care, mental health services or extra educational supports (Survey Questions 2, 2a, 2b)
 - C) Use or need for therapies (Survey Questions 4, 4a, 4b)

Unmet needs related to health consequences (Survey Questions 1c, 2c and 4c) are individually reported and combined with health consequences to describe a potential stratification model for CwCN. Health area(s) underlying functional or healthcare consequences (Survey Question 5) and Caregiver desire for help finding and organizing care if such a service were available (Survey Question 6) are individually reported.

Results

Demographics

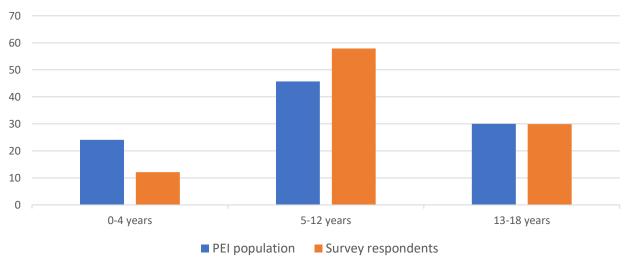
A total of 2060 surveys were returned. Of these, 200 were incomplete (i.e., did not respond to all 6 core questions) and were excluded from analysis. Thus, a total of 1860 surveys were included in this analysis. Queens County with the highest population had the highest number of respondents. Response rates for the 3 counties ranged from 5.6 to 7.1% with a 6.2% response rate from the province as a whole. Confidence levels and margin of error for population estimates are shown (Table 2).

Table 2. Response Rate, Confidence Level and Margin of Error

	Province	Kings	Queens	Prince
2020 PEI under 18-year-old Population	29826	3356	17796	8674
Number of Completed Surveys	1860	189	1055	616
% Completed Surveys / Total Population	6.2%	5.6%	5.9%	7.1%
Confidence Level	99%	95%	99%	99%
Margin of Error	3%	7%	4%	5%

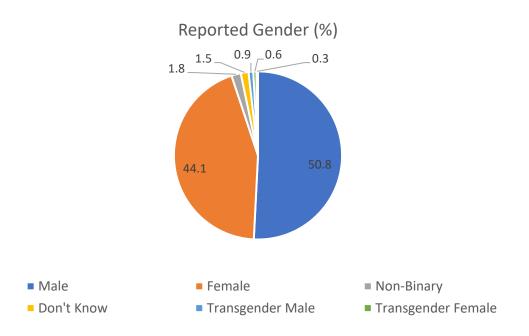
For the province as a whole, the 5–12-year-old group made up 45.7% of the population and accounted for 57.9% of respondents so were somewhat over-represented. This may reflect better sampling of the school age children due to the assistance of school partners during recruitment. In contrast, the 0-4-year-old age group made up 24.1% of the under 18-year-old population in PEI, but accounted for only 12.1% of respondents, so were under-represented in the survey. The 13–17-year-old group made up 30.0% of the population and accounted for 29.9% of the respondents.

Age Stratification of Respondents (%)



Males made up 50.9% of the under 18-year-old population according to Statistics Canada and accounted for 52.8% of respondents. Females made up 49.1% of the population and accounted for 47.2% of respondents.

Gender identification by respondents was: 50.8% male, 44.1% female, 1.8% non-binary, 1.5% don't know, 0.9% transgender male, 0.6% transgender female, 0.3% other.



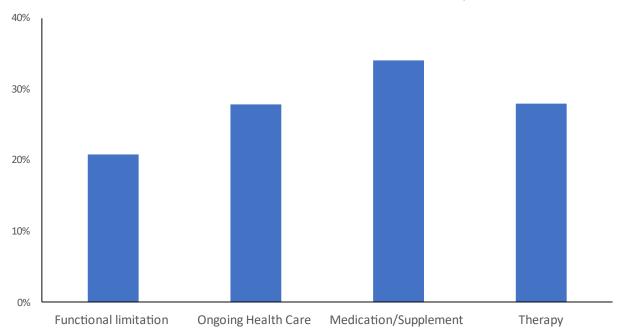
Weighting Plan

Weighting was applied to the survey samples to reflect a more accurate distribution of the PEI population, in order to obtain population-based estimates. The most updated PEI population estimates from Statistics Canada was obtained from PEI Statistics Bureau to determine the weighting scheme.

Functional Limitations and Health Consequences

The first 4 core questions sought to identify respondents with functional limitations or health consequences due to medical conditions lasting or expected to last over 12 months. These data were then combined to identify children meeting criteria for complex needs as described below.

Percentage of Respondents with Functional Limitations or Individual Health Consequences



Functional limitations due to a health condition lasting or expected to last over 12 months were assessed by **Question 3** "Is your child/youth limited or prevented in any way from doing the things they would like to do?" to which 426 respondents replied yes. However, 33 did not identify an underlying health condition (**Question 3a:** "Is this because of any developmental, medical, behavioral, emotional or other health condition?) and 7 did not meet the chronicity requirement (**Question 3b:** "Is this a condition that has lasted or is expected to last for at least 12 months?"). Thus, 386 respondents (20.8%) met criteria for Functional Limitations.

The health consequences related to Medication / Supplements were assessed by **Question 1:** "Does your child/youth currently need or use medicine or supplements prescribed by a doctor or other health care professional?" to which 600 respondents replied yes. However, 69 did not identify an underlying health condition (**Question 1a** "Is this because of any developmental delay, medical, behavioral, emotional or other health condition?") and 14 did not meet the chronicity requirement (**Question 1b:** "Is this a condition that has lasted or is expected to last for at least 12 months?"). Thus 517 respondents (27.8%) met criteria for the Medication / Supplement health consequence.

Similarly, health consequences related to Ongoing or Frequent Care were assessed by **Question 2** ("Does your child/youth need or use frequent or ongoing medical care, mental health services or extra educational supports?") to which 725 respondents replied yes. But 84 did not identify an underlying health condition and 9 did not meet the required chronicity criteria in **Questions 2a and 2b**, respectively. *Thus, 632 respondents* (34%) met criteria for the Ongoing Care health criteria.

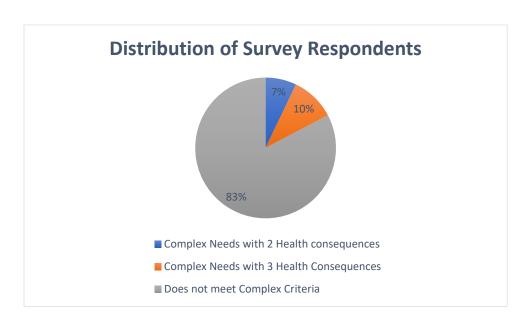
Finally, the health consequences related to Therapies were assessed by **Question 4** ("Does your child/youth need or get any therapies?") to which 599 respondents replied yes. But 65 did not indicate an underlying

condition and 15 did not indicate chronicity in response to **Questions 4a and 4b**, respectively. Thus, 519 respondents (27.9%) met criteria for the Therapy health consequence.

Respondents Meeting CwCN Criteria

The core questions above indicated that 20.8% of respondents had Functional Limitations and 27.8% to 34% of respondents had at least 1 health consequence. However, the Steering Committee definition of CwCN, required a functional limitation **and at least** 2 of the 3 health consequences described above. These criteria were met by 17.3% of the 1860 respondents of whom 41% (or 7% of all respondents) had Functional Limitations and 2 Health Consequences and 59% (or 10% of all respondents) had Functional Limitations and all 3 Health Consequences Based on the total under 18-year-old population, these findings suggest that there are 5174 CwCN on PEI of which 3031 have Functional Limitations and all 3 areas of Health Consequences.

More than 1 in 6 survey respondents met the criteria for having complex needs. These findings suggest that there are over 5000 CwCN on PEI



Unmet Needs/Access Difficulties

Respondents were asked about unmet needs related to health consequences in Questions 1c, 2c and 4c "In the past 12 months, did your child/youth experience any difficulties getting: medicine or supplements prescribed by a doctor or other health care professional (1c); medical care, mental health or extra educational supports (2c); getting therapy (4c). In total, 84% of PEI children with complex needs reported difficulties accessing at least 1 health services, 65% had difficulty accessing at least 2 services and 19% had difficulty accessing services in all 3 health consequences in the past 12 months. In addition, it is noteworthy that when considering all respondents, including those who did not meet CwCN criteria, 127 (24%) reported unmet needs related to Medicines / Supplements, 397 (62%) reported unmet needs related to Ongoing/Frequent Care, and 364 (68.3%) reported unmet needs related to Therapies.

5 out of 6 PEI children with complex needs reported difficulties accessing at least 1 health services

Stratification of CwCN by number of Unmet Needs and number of Health Consequences

CwCN identified during this survey were further stratified by combining Health Consequences and Unmet Needs (Table 4). CwCN at each level could have a wide range of medical needs and varied diagnoses. For example,

Level 1: Adolescent with anxiety with access to needed medication and receiving regular therapy, but still require assistance with activities of daily life.

Level 2: Child with Downs syndrome receiving ongoing Cardiology and Pulmonary care and Occupational Therapy (OT) but is unable to access needed Physiotherapy (PT).

Level 3: Child with Spinal Muscular Atrophy receiving regular OT, PT, and primary medical care, but unable to access Specialty Medical Care and Medication.

Level 4: Child with Cerebral Palsy with access to some therapies but not Speech Language Pathology, no access to medications for tone due to lack of funding, and access to some medical specialties but no access to pediatric neurology.

CwCN in Level 4 arguably face the greatest challenges in managing their healthcare and those in Level 1 the least, but other circumstances such as social determinants of health may affect CwCN at any of these levels. Thus, whether this stratification model alone might predict level of complexity and/or Navigator / Coordinator time remains to be determined.

Table 4. Stratification Model for CwCN

Healthcare	Healthcare Consequences with Unmet Needs			
Consequences	0 areas	1 area	2 areas	3 areas
2 Consequences	Level 1	Level 2	Level 3	
3 Consequences	Level 2	Level 3	Level 4	Level 4

Respondent Assessment of Health Conditions in CwCN

Core Question 5 asked "Please indicate which area(s) best reflect your child/youth's health care needs (select all that apply). Responses among the CwCN indicated a broad mix of 47% Medical Condition, 49% Behavioral Conditions, 61% Emotional Condition, 44% Developmental Delay, and 21% Other Health Condition.

Respondent Desire for Assistance

Responses to Core Question 6 "If there was a service available to help you find and organize care for your child/youth, would you use it?" were strongly positive with almost all (97%) caregivers responding that they would use this service, including caregivers of children who did not meet criteria as CwCN.

Conclusions

Children with complex needs are a relatively small population yet one that tends to use the health care system extensively. In summary, 17.3% of respondents met criteria for CwCN suggesting there are approximately 5174 CwCN under 18 years of age in PEI. By definition, all had functional limitations and 2 or 3 health consequences. A majority have unmet needs and almost all caregivers say they would avail themselves of a Service that assisted with access and coordination. These findings suggest that there are sufficient numbers and interest to support piloting a navigation / coordination service for CwCN in PEI. The Survey did not identify a particular area of health or combination of health consequences, but a potential stratification model that marries health consequences with unmet needs was described. While premature to suggest it be used as an enrollment tool, it may serve as a useful outcome marker as the service evolves.

Limitations

The temptation to draw further conclusions from this Survey must be tempered by its limitations.

- 1) Survey tool: The survey was based on the CSHCN Screener, a validated tool. However, there were several differences between the two. A focus group assessed the comprehensibility of the Survey, but its validity and reliability were not formally evaluated.
- 2) Scoring system: The survey was used to determine how many children under 18 years of age on PEI met the Steering Committee criteria for CwCN. These criteria seek to identify those most in need of navigation or coordination services. However, neither this nor the myriad other "enrollment criteria" based on administrative date, social or medical needs have achieved "gold standard" status (4-7). The criteria used in this survey may turn out to be too broad or restrictive in scope and require revision.
- 3) COVID: The Survey was administered during the COVID -19 Pandemic which may have skewed results a concern noted by multiple other surveys world-wide.
- 4) 0-4-Year-Old Group: Despite weighting of results, the under representation of 0-4-year-olds makes it difficult to be certain of the prevalence of CwCN in this age group.
- 5) Comparing populations: Although the number of respondents was sufficient to reliably estimate the population of CwCN on PEI, comparing sub-populations of the 332 CwCN identified would result in such small groups that statistical or real-world significance is unlikely.

Next Steps

- 1) Using the current data set, we propose to further describe respondents with 2 or 3 Health Consequences who did not meet Functional Limitations criteria.
- 2) Further improve and validate the Survey for future use in identifying CwCN and potentially as an outcomes tool, particularly if sufficient numbers of CwCN respond. Such work while difficult and time consuming, may be of value in evaluating a potential navigation / coordination service.
- 3) Use the current survey data to further develop a Navigation/care coordination program proposal.

Appendix A: CwCN Survey Health PEI Children with Complex Needs Survey Health PEI is committed to providing quality care to Islanders. Health PEI is asking caregivers of children/youth to complete the following survey. The information you provide will help Health PEI develop programs and services for children with complex needs and their caregivers. Your participation in this process is voluntary and only anonymous

information will be collected through the survey. Please do not include names or other identifying information in your responses.

Please fill in a survey for each child or youth <u>under the age of 18</u>, even those who have no health care needs. Fill in <u>one and only one</u> survey per child/youth.

Online version of this survey may be found at https://pei-children-health.questionpro.ca
If you have any questions or concerns about this survey, you may contact Colin Hood, Children with Complex Needs Coordinator, Public Health and Children's Developmental Services at 902-368-4952 or cdhood@ihis.org.

General Information about Child/Yo	outh_		
Age of Child/Youth	ge of Child/Youth years old (if child is under 1 year old, put "0")		
Place of Residence	□ Prince C	ounty	ounty
Language of preference	□ English	☐ French ☐ Other, please specify	
Sex of Child/Youth Assigned at Birth	□ Male	□ Female	
Gender as Identified by Child/Youth			
□ Male□ Female□ Transgender Female□ Intersex□ Other	ale 🗆 Non-E	Gender diverse/creative nary Don't Know	
Which of the following best describes the	racial or et	nic group of child/youth? (Select all that app	oly)
□ Asian - East (e.g. Chinese, Japanese, Korean) □ Asian - South (e.g. Indian, Pakistani, Sri Lankan) □ Asian - South East (e.g. Malaysian, Filipino, Vietnamese) □ Black - African (e.g. Ghanaian, Kenyan, Somali) □ Black - Caribbean (e.g. Barbadian, Jamaican) □ Black - North American (e.g. Canadian, American) □ First Nations □ Indian - Caribbean (e.g. Guyanese with origins in India) □ Indigenous/Aboriginal - not included elsewhere		 □ Inuit □ Latin American (e.g. Argentinean, Chilean, Salvadoran) □ Métis □ Middle Eastern (e.g. Egyptian, Iranian, Lebanese) □ White - European (e.g. English, Italian, Portuguese, Russian) □ White - North American (e.g. Canadian, American) □ Other(s), please specify □ Prefer not to answer 	
Health Information about Child/Yout	<u>:h</u>		
Does your child/youth currently need o care professional?	r use medic	ne or supplements prescribed by a doctor or	other health
☐ Yes Go to Question	on 1a	□ No Go to Question 2	

1a	Is this because of ANY	developmental delay, medical, be	ehavioral, emotional	or other health condition?
	□ Yes	Go to Question 1b	□ No	Go to Question 2
1b	Is this a condition that h	as lasted or is expected to last fo	r <u>at least 12 month</u>	<u>s</u> ?
	□ Yes	Go to Question 1c	□ No	Go to Question 1c
1c		did your child/youth experience ar or other health care professional?		the medicine or supplements
	□ Yes	Go to Question 2	□ No	Go to Question 2
2	Does your child/youth n educational supports?	eed or use frequent or ongoing m	nedical care, mental	health services or extra
	□ Yes	Go to Question 2a	□ No	Go to Question 3
2a	Is this because of ANY	developmental delay, medical, be	ehavioral, emotional,	or other health condition?
	□ Yes	Go to Question 2b	□ No	Go to Question 3
2b	Is this a condition that h	as lasted or is expected to last fo	r <u>at least 12 month</u>	<u>s</u> ?
	□ Yes	Go to Question 2c	□ No	Go to Question 2c
2c	In the past 12 months, of services or extra educations	did your child/youth experience ar tional supports?	ny difficulties getting	medical care, mental health
	□ Yes	Go to Question 3	□ No	Go to Question 3
3	Is your child/youth limited	ed or prevented in any way from o	loing the things they	would like to do?
	□ Yes	Go to Question 3a	□ No	Go to Question 4
3a	Is this because of ANY	developmental delay, medical, be	ehavioral, emotional	or other health condition?
	□ Yes	Go to Question 3b	□ No	Go to Question 4
3b	Is this a condition that h	as lasted or is expected to last fo	r <u>at least 12 month</u>	<u>s</u> ?
	□ Yes	Go to Question 4	□ No	Go to Question 4
4	Does your child/youth n	eed or get any therapies?		

	□ Yes	Go to Question 4a	□ No	Go to Question 5
4a	Is this because of ANY	developmental delay, medica	al, behavioral, emotional	or other health condition?
	□ Yes	Go to Question 4b	□ No	Go to Question 5
4b	Is this a condition that I	nas lasted or is expected to la	ast for <i>at least 12 month</i>	<u>ıs</u> ?
	□ Yes	Go to Question 4c	□ No	Go to Question 4c
4c	In the past 12 months,	did your child/youth experien	ce any difficulties getting	therapy?
	□ Yes	Go to Question 5	□ No	Go to Question 5
5	Please indicate which area(s) best reflect your child/youth's health care needs. (Select all that apply)			
	□ Medio	cal		
	□ Beha	vioural		
	□ Emotional			
	□ Developmental Delay			
	☐ Other Health Condition, please specify if known:			
6	If there was a service available to help you find and organize care for your child/youth, would you use it?			
	□ Yes		□ No	

Thank you very much for completing this survey!

This will help us develop and plan programs to better serve children/youth and caregivers.

If you have any questions or concerns, please contact Colin Hood,
Children with Complex Needs Coordinator, Public Health and Children's Developmental Services
Phone: 902-368-4952 / Email: cdhood@ihis.org

Appendix B: Children with Special Health Care Needs (CSHCN) Screener©

Children with Special Health Care Needs (CSHCN) Screener© (mail or telephone)

1. Does your child currently need or use medicine prescribed by a doctor (other than vitamins)?

Ĩ Yes
② Go to Question 1a

No 2 Go to Question 2

1a. Is this because of ANY medical, behavioral or other health condition?

Tyes 2 Go to Question 1b

No 2 Go to Question 2

1b. Is this a condition that has lasted or is expected to last for at least 12 months?

Ĩ Yes

ĨΝο

2. Does your child need or use more **medical care, mental health or educational services** than is usual for most children

of the same age?

Tyes 2 Go to Question 2a

No 2 Go to Question 3

2a. Is this because of ANY medical, behavioral or other health condition?

Tyes 2 Go to Question 2b

No 2 Go to Question 3

2b. Is this a condition that has lasted or is expected to last for at least 12 months?

آYe

ĨΝο

3. Is your child **limited or prevented** in any way in his or her ability to do the things most children of the same age can do?

Tyes @ Go to Question 3a

No 2 Go to Question 4

3a. Is this because of ANY medical, behavioral or other health condition?

Tyes 2 Go to Question 3b

No 2 Go to Question 4

3b. Is this a condition that has lasted or is expected to last for at least 12 months?

آYes

ĨΝο

4. Does your child need or get special therapy, such as physical, occupational or speech therapy?

Tyes 2 Go to Question 4a

No 2 Go to Question 5

4a. Is this because of ANY medical, behavioral or other health condition?

Tyes 2 Go to Question 4b

Ño 2 Go to Question 5

4b. Is this a condition that has lasted or is expected to last for at least 12 months?

آYes

ĨNo

5. Does your child have any kind of emotional, developmental or behavioral problem for which

he or she needs or gets treatment or counseling?

Tyes 2 Go to Question 5a

ĨΝο

5a. Has this problem lasted or is it expected to last for at least 12 months?

Ĩ۷es

Nox B: CSHCN Screener

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