

Children and Youth with Special Needs Population Study

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CREE BOARD OF HEALTH AND SOCIAL SERVICES OF JAMES BAY

November 2010

Acknowledgements

This population study is the result of many months of collaboration between numerous people who share one dream: improving the quality of life of children and youth with special needs in Eeyou Istchee. We are proud to say that this report is the result of a partnership between the Cree Board of Health and Social Services of James Bay, the Cree School Board and the Cree Regional Authority.

We want to acknowledge the support and collaboration of the members of the Advisory Committee, who provided regular guidance and feedback, ensuring the completion of this project.

We also want to express gratitude to the people with special needs and their caregivers who each spent multiple hours sharing their stories with the interviewers.

Amongst others, special regards go to:

- *The elders who guided our thoughts through the entire process*
- *The people with special needs and their families*
- *The thirty-one (31) interviewers from the nine (9) Cree Communities*
- *The Occupational Therapists, Physiotherapists and Psycho-Educators*
- *The employees of the three (3) entities: CHB, CSB and CRA*
- *The Managers who shared precious human resources, in addition to their own time*
- *The Chiefs and the Band Councils*

Finally, we wish to thank all the others, too numerous to mention, who contributed in some ways towards the completion of this project.

The necessity to provide quality services to youth with special needs in Eeyou Istchee is recognized as a priority by many local entities. A vast population study was conducted to identify strategies to improve the quality of care provided to people between 0 and 29 years of age, who are living with physical, intellectual, mental or socio-emotional impairments.

During the period extending from September 2008 to May 2010, five hundred (500) children and youth with special needs were identified. One hundred and ninety-one (191) families accepted to complete a detailed questionnaire addressing many aspects of the individual's life. Fifty-eight (58) main recommendations were made following interpretation of the data. Most of the recommendations concern the Cree Board of Health and Social Services of James Bay (CBHSSJB). However some issues will be addressed to the Cree School Board (CSB), Cree Regional Authority (CRA) and the Band Councils.

According to the profile of the population surveyed, the number of special needs individuals under the Awash and Uschinischuu programs is similar (Awash 216/Uschinischuu 266). Therefore, leaders from both programs should be sensitized to the necessity to develop services for that clientele. However, the nature of the needs in each age group differs. Nearly half of the children (0-9 years old) appear to be developmentally challenged (100/216). The most frequently reported conditions for that age group are: learning and language delays, autism, and global developmental delays. Older individuals in the study group appear to be more impacted by physical disabilities (58/266) or experience socio-emotional difficulties (48/266).

Overall, the situation of the children and youth with special needs in Eeyou Istchee can be resumed by stating that at the present time there is a global lack of services being provided to this vulnerable population. The services that are presently provided are insufficient to significantly improve the quality of life and/or condition of the individuals and their family. Moreover, the services provided are generally not coordinated amongst the entities, which generates confusion amongst the care providers and the family members. Although the participants were generally satisfied with the actual medical

services received (by their doctor, therapist, nutritionist, etc.), holistically, their needs were not being answered and their families were not receiving the services needed. Most of the families caring for individuals with special needs are in crisis. The familial network of the individuals with special needs is rarely sufficient to compensate for the lack of professional services. Many caregivers are overwhelmed by the situation. After years of trying to compensate for the lack of services, many need psychological support themselves. Over an extended period, the lack of support to the natural caregivers also causes an increased demand for foster care, respite, placement outside of the territory and schooling in urban areas. Respite care is amongst the most frequently demanded services by the families who are caring for severely handicapped children. Often, the families are struggling to the point that they are ready to accept placement outside of Eeyou Istchee although it is not perceived as the ideal solution for psychological, socio-emotional, and cultural reasons. Implementation of local respite resources is crucial in order to adequately support the families.

Various measures could be implemented to improve the quality of life of the individuals with special needs in Eeyou Istchee. Among others, prevention program (Fetal Alcohol Spectrum Disorder (FASD)), early stimulation programs, local access to rehabilitation services (Specialized Education, Occupational Therapy, Physiotherapy, Speech Therapy), respite services, summer day camps accessible to individuals with special needs and vocational training could have a positive impact on the global situation.

However, the single measure that has the most significant impact on the current state of affair is the implementation of case management. A specific person must be identified to represent each individual with special needs and follow the continuation of care of their file at the CBHSSJB. At this point in time, many interventions are never completed, reports rarely presented and care not provided due to lack of communication between the care providers. Case Managers must be identified and trained to lead interdisciplinary interventions, maintain communication between the care providers through adequate use of the medical file and networking with the family, school and Child Care Centers. Awash and Uschinischuu programs must be confirmed in their role and responsibilities towards to provision of direct services to individuals with special needs.

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LIST OF ABBREVIATIONS

CBHSSJB	Cree Board of Health and Social Services of James Bay
CPS	Cree Patients Services
CRA	Cree Regional Authority
CSB	Cree School Board
ICU	Intensive Care Unit
IEP	Individual Educational Plan
K4	Pre-kindergarten
MCH	Montreal Children Hospital
MEQ	Ministry of Education of Quebec
MSDC	Multi-Services Day Centre
RAMQ	Régie de l'Assurance Maladie du Québec

GLOSSARY

Eeyou: Name used to identify the First Nation people native of James Bay area.

Eeyou Istchee: Name given to the territory occupied by the Cree communities of Northern Quebec.

Foster Care: Term used for a system in which a minor is placed in the private home of a caregiver, other than the biological parents, referred to as a "foster parent". Foster Care is intended to be a temporary solution, until the child is reunited with the biological parents or adopted.

Miyupimaatisiwin: State of good health, well-being and wellness in the language of Eeyou.

Multi-Services Day Centre: Activity centre accessible to adults of all ages, afflicted by any type of disability (physical, intellectual, psychological), to promote autonomy, limit isolation, encourage community integration, develop the skills necessary to integrate the work force and to receive rehabilitative services.

Respite Care: Short-term, temporary relief to those who are caring for family members who might otherwise require permanent placement in a facility outside the home.

Special Needs: Term used to describe individuals who require assistance for disabilities that may be medical, mental, or psychological. Special needs also refers to special needs within an educational context. In Germany a similar term exists. Special needs kids are referred to as "special children".

INTRODUCTION

At this point in time, very few services are accessible to people with special needs in Eeyou Istchee. Many entities are making isolated attempts to address the needs of the most vulnerable individuals of the population, often using resources acquired to serve the rest of the population.

This study describes the needs of individuals of less than thirty (30) years old who live in Eeyou Istchee and are affected by a long-term condition. The report is intended to provide an insight to the types of services that would be necessary to improve their quality of life to meet basic Canadian standards.

The recommendations expressed in this report are based on the following five (5) guiding principles that are believed to reflect the values of most entities providing services in the region:

1. Optimal quality of life is best achieved when the individual remains within his/her community of origin, where his/her natural network support is already well established. A continuum of care should range from community-based services to outside and/or off territory services;
2. The individual with special needs and his/her family have a unique understanding of the person's situation. They are active partners in the provision of services and should be involved at decision-making level;
3. The person's need is the primary determinant of the nature, level of service and appropriate location for service delivery;
4. Clients entering the formal health and community support network through current services are assessed by health and social service professionals and are then referred to the appropriate program depending on their age. This ensures that individuals are directed to the level and nature of service that is most beneficial for their needs and there is a process in place whereby the client's needs are reassessed at appropriate intervals;

5. Each entity providing services to the person is an expert in its own sector of activity. Interagency collaboration ensures the delivery of optimal care to the person. Services are perceived as being complementary and should not be duplicated.

1. THE REGION AND ITS PEOPLE

1.1 General

Eeyou Istchee is a vast sub-artic zone that extends in the northern region of Quebec, from the 49th parallel to the 55th parallel. It is sometimes referred to as the James Bay region. People native to the region refer to themselves as “Eeyou” and there are archaeological findings indicating that they lived in this area for at least 5,000 years. The Crees (Eeyou) lived a semi-nomad lifestyle until the arrival of the Europeans, in 1853. They now live in nine (9) communities, spread over 350,000 square kilometres of territory. Hunting and fishing still occupies a predominant part in the lifestyles of the Crees.

1.2 Demographic Data

The Cree population, which accounts for 97-99% of the residents of Eeyou Istchee, is known with considerable precision on account of an official Cree Beneficiaries list, maintained between the Government of Quebec and the Cree Council office. The population of James Bay is young and rapidly growing. From 9,078 inhabitants in 1990, the population increased to 14,731 persons in 2008 (Appendix 1). People of less than 20 years of age represent forty-four percent (44%) of the total population. In the communities of Mistissini and Chisasibi, there are well over one thousand individuals of that age group.

As population is increasing over time, it is expected that number of people with special needs will also increase. For that reason, all numeral figures presented in this document are considered as being extremely conservative. Services should be planned and developed with the idea that the actual number of users will be bigger than what is presented in this document.

Table 1: Distribution of people 0-19 years old in Eeyou Istchee, in 2008

Community	Individuals 0-19	Total Population	Percentage
Whapmagoostui	401	829	48.4%
Chisasibi	1701	3924	43.3%
Wemindji	505	1277	39.5%
Eastmain	263	630	41.7%
Waskaganish	920	1977	46.5%
Nemaska	190	659	28.8%
Ouje Bougoumou	320	676	47.3%
Mistissini	1428	3232	44.2%
Waswanipi	709	1527	46.4%
Total	6518	14731	44.4%

1.3 Traditional View on Health

A health plan should reflect and respect the culture of the people being served. Because the Crees have a distinct culture, the services proposed should correspond to beliefs and values of the Cree culture. Culture is understood to be the whole way of life of people.

The word “miyupimaatisiiwin” best describes the state of good health, well-being and wellness in the language of Eeyou. “Miyupimaatisiiwin” literally means “healthy life”. It integrates and gives equal emphasis and importance to the physical, emotional, mental and spiritual aspects of the person. It is a vision quite different from that of contemporary health and social services, which tend to isolate problems and treat them separately. For young people who are receiving services from the Community Miyupimatisuun Center, school and/or child care centre, collaboration between the entities, community, and family is essential to the achievement of that global state of health.

The person, family and community constitute the foundation of Eeyou people and nation. The Eeyou family is the central institution of the Eeyou community and is more than the biological unit of parents and children in a dwelling. The Eeyou family encompasses the extended framework of grandparents, aunts, uncles, in-laws, cousins, and adopted relatives. The elders play a unique role of providing guidance and ensuring Cree teachings on living a miyupimaatisiiwin (healthy) life style. Their opinions and teachings

are valued and respected. The Cree people also have a strong connection to one's respectable community. For this reason, the integration of Cree people with special needs into their own community is even more meaningful. All efforts should be made to provide services locally.

2. THE PLAYERS PROVIDING SERVICES TO THE CHILDREN AND YOUTH WITH SPECIAL NEEDS

The Grand Council of the Crees is the political body that represents the Crees of James Bay area. The Cree Regional Authority (CRA) is the administrative arm of the Grand Council of the Crees. It has responsibilities in respect to environmental protection, hunting, fishing and trapping regime, as well as economic and community development. Amongst others, the CRA is responsible for administering the Child Care Centres.

The Cree Board of Health and Social Services of James Bay (CBHSSJB) has jurisdiction and responsibilities for health and social services for all persons normally resident or temporarily present in Eeyou communities and on Eeyou land. It presently has a regional hospital centre and eight clinics. The CBHSSJB has a Public Health Department with the mandate of preventing disease and protecting, measuring and promoting the health of the population. In the area of social services, the CBHSSJB operates youth group homes in Chisasibi and Mistissini and a regional youth rehabilitation centre in Mistissini.

The Cree School Board has jurisdiction and responsibility for the education and training of all resident of Eeyou Istchee. The Board provides services to over 3,600 students at the primary, secondary and post secondary levels. It has implemented a distinctively Cree curriculum in geography, history, and economics and established in service training for Cree teachers. Efforts are under way to develop a land based Cree hunting and trapping vocational option.

The Band Councils are also important partners for the provision of services to the people with special needs. They are generally in charge of the housing, access and maintenance of public buildings and roads, recreational programs (including summer camps) and public safety. They also provide assistance with governmental programs such the social security program, brighter future and health community program.

3. OVERVIEW OF THE POPULATION STUDY

The purposes of the Special Needs Population Study were to establish a list of people with special needs in Eeyou Istchee, clarify the nature of their needs, and emit sensible recommendations to the entities providing them services. The long-term goal is to improve the quality of life of the children and youth with special needs. In order to improve the state of well being of these special individuals, a global approach to care must be used. All needs must be considered as interrelated and cannot be dissociated from each other. This enhances the necessity for the entities to work collaboratively.

3.1 Historical perspective of the project

The necessity of completing the Special Needs Population Study became obvious following the Regional Special Needs Conference in 2007. The caregivers frequently reported feeling isolated. They often thought that no one else was experiencing a situation similar to theirs. They deplored the lack of services and the necessity to constantly rely on resources not available locally. Since their children often received services from multiple care providers, they commented on the obligation to regularly retell their story. They expressed the wish of receiving adequate services that would not only impact on the quality of life of their child but also have positive repercussions of their family and community life.

3.2 Methodology

The project is a vast qualitative study. It began by a public consultation in each community (fall 2008). A total of 516 children and youth who have special needs were identified as potential candidate for the project (Spring 2009). Each family was individually contacted and interviewed to complete a lengthy survey (144 questions) with the help of a trained interviewer (Winter 2009-2010). One hundred and ninety-one (191) people completed the questionnaire. The communities should be visited to present the final results (fall 2010).

For the purpose of the study, only people with permanent conditions were interviewed. However, when developing services, the fact that many other people may temporarily present with a similar problem should be considered.

3.3 Profile of the Children and Youth with Special Needs

Review of the literature provides multiple definitions and categories of special needs. For the purpose of this study, special needs has been defined as “Individuals who require assistance to meet their basic needs because they have a long-term, chronic condition which affects their capacity to achieve their full potential intellectually, physically, cognitively and/or socio-emotionally”.

Although most chronic conditions affect all aspects of the individual life, the needs have been divided into six (6) categories to facilitate presentation of the results (Appendix 2):

Physical: Conditions that affects primarily the body of the person affected (e.g. congenital malformation, juvenile rheumatoid arthritis).

Developmental: Conditions that are directly linked to an incomplete maturation of some aspects of the person (e.g. fine motor delays, language impairments).

Socio-emotional: Conditions that are linked to the past or present environment into which the person evolves. The manifestation of these impairments would possibly be different in another setting or under different social norms (e.g. attention deficits, post-traumatic stress disorder).

Cognitive: Intellectual limitation that affects the person’s capacity to learn and answer his/her basic needs autonomously (e.g. Down Syndrome, some birth anoxia)

Mental: Conditions that affects the person’s capacity to control his/her emotions, to interact socially, and/or to perceive themselves and others (e.g. schizophrenia, eating disorders)

Multiple: Conditions that largely impact on more than one (1) aspect of a person’s life (e.g. Cerebral Palsy).

Services for people with special needs should be developed evenly under the Awash and Uschinichisuu programs since the number of people with special needs to be served under each program is high (Awash: 218, Uschinichisuu: 265).

Table 2: Needs of the individuals between 0-9 years old under each category

	Physical	Developmental	Socio-emotional	Cognitive	Mental	Multiple	Unknown	Total
Chisasibi	10	30	3	2	0	6	9	60
Eastmain	2	0	5	1	0	0	1	9
Mistissini	7	15	1	0	0	1	2	26
Nemaska	0	0	0	0	0	0	3	3
Ouje Bougoumou	0	0	0	0	0	0	2	2
Waskaganish	6	22	4	1	0	4	4	41
Waswanipi	16	18	1	0	1	3	7	46
Wemindji	3	12	0	2	0	0	5	22
Whapmagoostui	1	2	3	0	0	3	0	9
Total	45	99	17	6	1	17	33	218

Table 3: Needs of the individuals between 10-29 years old under each category

	Physical	Developmental	Socio-emotional	Cognitive	Mental	Multiple	Unknown	Total
Chisasibi	5	7	8	20	0	7	3	50
Eastmain	3	5	3	0	0	2	0	13
Mistissini	8	11	5	10	6	1	4	45
Nemaska	0	2	2	0	0	0	13	17
Ouje Bougoumou	1	1	2	0	0	0	6	10
Waskaganish	8	5	12	3	1	9	3	41
Waswanipi	22	5	5	5	3	8	2	50
Wemindji	6	3	4	2	0	3	2	20
Whapmagoostui	4	1	7	2	0	1	4	19
Total	57	40	48	42	10	31	37	265

The analysis of these data may be important to determine in which community new services should be developed. Each community as a “special needs profile” that appears to be unique. Amongst the study population, one (1) person out of four (4) is experiencing a developmental delay. Chisasibi and Waskaganish present with the largest number of children (0-9 years old) with developmental delays. The number of teenagers and young adults with cognitive limitation in Chisasibi is important (20 individuals). In Waswanipi, it is the number of teenagers and young adults with physical limitations that raises concerns (22 people). One quarter (24%) of the people who are socio-emotionally challenged are from Waskaganish.

In addition to the needs identified by the population study, attention should be given to other factors when planning future resources. The emergence of social phenomena that were almost inexistent a few decades ago, such as consumption of illicit drugs and easier access to alcohol will directly impact on the number of children and youth with special needs in the future.

3.4 Children and Youth with special needs outside of Eeyou Istchee

Children and youth who are severely affected by disabilities sometimes cannot be served within the communities. The most frequent reasons that justify long-term placement outside of Eeyou Istchee are educational needs that exceed the capacity of the local school, needs for regular medical treatments, necessity to provide constant (24h/day) supervision and health issues that are likely to require immediate medical attention (haemophilia).

The exact number of children and youth who live outside of Eeyou Istchee due to educational or health needs is unknown because some families choose to make that important life change on their own. However, many people who live outside of the territory do so with the financial support of the CBHSSSJB and/or CSB. Most people in that situation move to Montreal, Gatineau or Hull.

It is well known by the services providers that the financial cost of supporting people outside of the communities is very high and that all should be done to prevent or postpone this situation. Moreover, the personal and emotional charge of moving to a foreign town or to send a child to a foster home cannot be measured.

4. RESULTS OF THE POPULATION STUDY

The purpose of this section is to present the main results of the study and to propose various solutions to difficulties that were reported. When possible, the frequency at which the situation was reported by the caregivers is specified. The reader should keep in mind that those situations were reported by the primary caregivers but not validated with the various entities providing the care. In some occasions, the problem might have been due to uncontrollable circumstances. The purpose of the population study is not to judge the efficiency of the entity providing the services but rather to establish ways to improve the clients' overall satisfaction.

4.1 Cree Board of Health and Social Services of James Bay (CBHSSJB)

4.1.1 General Services

In the last few years, the CBHSSJB has significantly grown and diversified its services. It went from small local clinics to bigger buildings providing a wide range of services divided by age groups (Awash, Uschinichisuu, and Chishaayiyuu). For people with special needs, all this is good news. It means that they will now be able to receive services that were previously unavailable to them. The full implementation of these new services is not yet completed and already, clients are feeling a little lost when trying to navigate into this bigger pool of services.

This is especially true for people with special needs since they are often using services from multiple health care providers. Caregivers reported the need for a single person to contact in order to follow all the activities in their medical and social files. According to the caregivers' comments and feedback, the single most efficient measure to improve the quality of care provided by the CBHSSJB would be the implementation of Case Management.

At this point, the lack of coordination amongst the services providers within the CBHSSJB as well as with the CSB and CRA causes various difficulties. Amongst others, it results in some services not being provided, redundancy in other services, too many intervention goals, lack of a holistic approach and worst of all, discourages the parents.

Having a single person in charge of each special needs patient's file would partly solve many of these complaints. It would facilitate the implementation of a multidisciplinary intervention team, which is necessary to ensure that all the needs of the person are address and to avoid duplication of services. It would also facilitate the exchange of information between health care services and social services providers. At this point in time, it appears that many people with health issues are not receiving adequate emotional support (69.8%) because there are no mechanisms in place to systematically inform the Social Services department of all patients newly diagnosed with a chronic, long-term condition. Lack of support at that crucial point in life may have long term consequences that not only affects the person with special needs but its entire family.

Case Management would facilitate the transmission of information between Cree Patient Services (CPS) and the local clinics. Multiple comments were made concerning the difficulties to access information from CPS.

Case Management could bring around the discussion table service providers from the CBHSSJB, CSB and CRA who are caring for the same person. Efficient transmission of information between the various entities would likely result in an increase of services and financial resources for the person with special needs. For example, the school largely benefits from being informed of any long-term, chronic diagnosis established for a child. This enables them to receive additional funding from the Ministry of Education (MEQ) to better assist the child.

A Case Manager could also ensure that normal care, not necessarily due to the special needs, are being provided following the usual schedule. For example, a large percentage of the children and youth with special needs reported not having received dental care for more than two (2) years. The Case Manager would ensure that all aspects of the person's care are being address to the same extent as other community members.

Case Management was successfully attempted in Mistissini. There is now one person in charge of overseeing the files of a few people with special needs. It is believed that her involvement will result in a decreased number of "no shows" to appointments outside of the communities, increase financial help to the school and families, increase emotional

support, facilitate the access to special programs such as summer camps and respite care, and cause an overall improvement of the patients' quality of life.

All efforts should be made to facilitate the communication between the CBHSSJB, CRA and CSB. The lack of communication directly impacts on the services provided to the children. It results in some services not being provided while others are being duplicated. In some cases, it results in inadequate and unfair funding. The poor transmission of information appears to sometimes be the result of an attempt to preserve confidentiality. The CBHSSJB should ensure that all information to properly care for a child is transmitted to all entities involved. This includes transmission of diagnosis, explanation of the interventions done with the child, statement of the long-term goals and objectives and description of the financial help provided by the entities to the families. Respecting confidentiality should not be a barrier to the provision of adequate services.

In the current system in place in Eeyou Istchee, it is frequent that appointments at the local clinic, as well as outside of the territory, are scheduled for the patients without them taking an active role in the scheduling. Only 26% of the participants said that they are informed before an appointment is made on their behalf. Typically, patients are given a very short notice before the appointment time. Forty-three percent (43%) of the respondent said that they are usually notified only on the day of the appointment. More than half of the families (58% expressed the wish to be informed, at least one week in advance, when an appointment has been made on their behalf. When the appointment is outside of the community, two (2) or three (3) weeks notice would be preferred.

A current policy of the Challenger (plane used for emergency evacuations) prohibits the boarding of an escort. This implies that children transferred for health emergencies with that plane are left alone in Montreal or Val d'Or until the escort, sent out on a regular flight, arrives. In addition to being extremely stressful for the child sent alone, this situation can be dangerous for the parents, who sometimes decide to drive to meet their child sooner than they would if boarding the next scheduled flight (often the next day). All efforts should be made to avoid this situation.

Finally, it appears that monies, available through various provincial and federal programs to help people with special needs, are often not used by residents of Eeyou Istchee. Amongst others, there are programs to help victims of road accidents (SAAQ), facilitate house adaptation (PAD), increase personal revenue in case of chronic illness and facilitate employment by offering a financial compensation to the employer of people with certain disabilities. Only ten percent (10%) of the respondents appear to be benefiting from those programs. In Eeyou Istchee, the CBHSSJB or other entities often assume the financial costs of these services. It could be financially interesting for the CBHSSJB to ensure that all eligible candidates take advantage of those programs before being compensated by the CBHSSJB.

4.1.2 Cree Patient Services

Cree Patients Services (CPS) employees are very much involved with the people with special needs. They are the link between the local clinics and the hospitals outside of Eeyou Istchee, mainly in Chisasibi, Val d'Or, Montreal and Chibougamau. They receive all the referrals for external medical services, book the appointments, make the necessary travel arrangements, prepare the traveling claim, and transmit the reports to the communities. They also oversee the services provided by the Boarding Houses. There are CPS employees in each Community Miyupimatisuun Center as well as in Val d'Or, Montreal and Chibougamau. For the most parts, caregivers appear to be satisfied with the services received directly from CPS agents. In general, they appreciate the fact that all the arrangements for the trip are made for them as well as the help to submit travel claims.

However, the quality of the services provided at some boarding houses is not satisfactory to many tenants. Complaints are mainly related to the lack of privacy, too large number of tenants for the capacity of the house, unsatisfactory meal services and too rigid house rules. Reports of being forced to share bedrooms, and sometimes-even beds, with strangers were frequent. Insufficient number of bathrooms, lack of food, leftovers being served repetitively, and mattresses set right on the floor were some of the frequent recriminations. Above all those, the fear that their child with special needs might strongly react to the presence of strangers, the constant noise or the lack of personal space and starts crying or screaming appears to generate anxiety for the caregivers. Some parents

reported being kicked out to the street, in the middle of the night, because of a crying child.

Some parents are offered the possibility to stay at the hotel (49 respondents), others decide to do so on their own (34 respondents). Those who decide to stay at the hotel usually do so because of the nature of their child's needs, because they are traveling with more people than the number of escorts assigned by CPS (19%) or for other personal reasons. Those who are offered a place in a boarding house but decide to stay at the hotel do not receive financial assistance to cover their expenses. One out of two respondents (50%) expressed the wish to receive a financial compensation equivalent to the price paid by the CBHSSJB to the Boarding House.

Parents often reported that the number of escorts authorized to travel with the person with special needs is insufficient (57 respondents). They mentioned the necessity to take into consideration that it is more difficult to care for a child with special needs outside of their regular environment. Adapting to new situations such as taking the plane, riding in a taxi, sleeping in a new room and being constantly surrounded by strangers generates anxiety for many children, notably those with attention deficits, cognitive and mental impairments and behavioural disorders.

Instances when young adults afflicted by cognitive or mental impairments were sent out, without an escort, for medical appointments outside of the community have been reported twice. In both cases, they were sent out for appointments not related to the nature of their special needs (e.g. Twenty years old man with mild cognitive impairment sent out for a gastroenterology appointment). Although those young adults function autonomously within the communities, they were not trusted by their natural caregivers to safely handle the challenges inherent to big cities such as not getting lost, easy access to gambling, drugs, alcohol, prostitution and infinite spending opportunities.

The parents often mentioned that they are not aware of the status of their files at CPS. They reported a lack of information related to the result of their appointments. They often do not know if a follow-up appointment is needed and, in the affirmative, the suggested timeframe for the next visit. Finally, they reported not receiving physical and emotional

support in the community, following an appointment outside of Eeyou Istchee (60 respondents). This appears to be especially important if a new, long-term, chronic diagnosis was made.

4.1.3 Social Services

Being informed that a loved one will need special care is a stressful situation for many caregivers. Lack of support following the establishment of the diagnosis is often reported. At that time, families are often overwhelmed. They do not fully understand what the diagnosis is and how it is going to affect their life. They are sometimes left with nobody to talk to. It is believed that Social Services can play a crucial role to support the families. They can offer direct counselling services. They could also use other strategies such as support group, pairing of parents facing similar situations or online discussion groups to help the parents.

Caring for a person with special needs has serious impacts on a person's life. The families reported that most aspects of their social life are affected. Although they generally find emotional support within their families and friends, many of them reported feeling of exhaustion, burnout or chronic fatigue. They often feel alone with the responsibility of caring for the person with special needs. Many of them cannot count on families, friends, or respite care to take over for one (1) or two (2) nights. Respite services for people with special needs should be offered in one's community. Most families said that they would not use respite care in another community (63%).

Moreover, many of them do not have a long-term plan that identifies who could take care of the person with special needs if the current caregiver was permanently ill or deceased (38%). This very serious issue should be addressed in the patient's care plan.

The parents' capacity to work is often limited by the condition of the person with special needs. In some instance, one parent must stay home to provide the basic care. This has a direct impact on the income of the family.

Following the news of the pregnancy or the birth of the child, first time parents and young parents are often overwhelmed by their new responsibilities (special needs or not). A program should be in place to prepare and support new parents.

Implementing a routine and dealing with disciplinary issues appears to be a challenge in many families (special needs and others). The number of families dealing with children or young children who present behavioural difficulties is very high. Although it might not solve the problems, prenatal classes and parental workshops might raise the confidence of the parents in their ability to address the issues. This appears to be specifically important for young parents, first time parents and adults caring for step-children or children in foster care.

The families currently receiving services from the Social Services department appear to be satisfied with the services provided. However many families are not receiving services. When asked if they would prefer to receive services from native people or non-native people, most caregivers answered that it does not matter, as long as the worker has the necessary skills and expertise (63%). Therefore, training of employees should remain a priority.

Situations where children with special needs or their sibling were sick and not brought to the clinic have been reported. This seems to happen mainly due to lack of caretaker for the healthy children. A bank of emergency babysitters for normal children as well as for children with special needs could be developed.

Financial requests to the CHB and CSB are frequent and numerous. However, many parents are not applying for governmental programs that provide financial assistance to people with special needs. Social services workers should be aware of the various governmental programs offering financial assistance and should assist the families in accessing those funds.

4.1.4 MSDC Services

The Multi-Services Day Centres (MSDCs), in operation in all communities, have been designed to provide rehabilitative, recreational and vocational services to adults with special needs. Similar services are necessary for children and youth with special needs. There are many requests made for after school services and services during school closure. In most communities, the after school program run by the CRA does not have the resources to serve children with special needs. Most extracurricular programs (e.g. skating, basketball, badminton) are not designed to accommodate children with special needs and are not staffed accordingly. During the summer, day camps offered in the communities are generally not able to provide shadows or special groups to these children either. Moreover, caregivers often reported that their children are socially excluded. They cannot always participate in community events such as Mamewdow, Pow-Wow, and barbecues because of the noise and large crowds (37%).

The Multi-Services Day Centres represent a safe and secure environment where children and youth with special needs could develop their potential to the maximum of their capacity. Most MSDCs receive adult clients only for restricted hours of the day (10am to 3pm). Moreover, the volume of users appears to be lower than the initial expectation in most communities. The possibility to use the building and employees, at different times, for both age groups should be considered.

At least one community uses the MSDC building to provide services to a young person who cannot function in the school environment. The presence of the child, at the same time as the elders, does not appear to cause any difficulties.

The MSDC could review the current schedule to accommodate adults during daytime and school age children after school hours. The MSDC program should be reviewed to integrate occasional activities for children and youth with special needs during weekends or pedagogical days. During the summer months, the MSDC schedule could be revised to serve both elders and children (e.g. half-day each).

4.1.5 Services for people with physical limitations

A total of one hundred and two (102) children and youth with special needs are living with physical limitations.

Table 4: Children and youth with physical limitations

	Awash	Uschinichisuu	Total
Chisasibi	10	5	15
Eastmain	2	3	5
Mistissini	7	8	15
Nemaska	0	0	0
Ouje Bougoumou	0	1	1
Waskaganish	6	8	14
Waswanipi	16	22	38
Wemindji	3	6	9
Whapmagoostui	1	4	5
Total	45	57	102

Many of these young people are experiencing kidney problems, spina bifida, epilepsy, diabetes and respiratory difficulties. Thirty-seven percent (37%) of the youth facing physical difficulties are from Waswanipi. These data reinforce the need for the provision of health care services within the schools.

Rehabilitation services such as Occupational Therapy and Physiotherapy are very important for people with physical handicap. It often makes the difference between preserving the autonomy to care for oneself and being dependent on others for personal care. At this point in time, many communities still do not have local resources available for rehabilitation services. Those communities either rely on visiting therapists or send the patients out for services in Chibougamau, Val d'Or or Montreal. Rehabilitation services are most efficient when provided on a regular basis (a few times a week). All effort should be made to the services locally. When establishing the financial cost of purchasing these services, it should be remembered that preserving autonomy for the client means a decrease in the needs for Home Care services, Nursing services and respite care services.

4.1.6 Services for people with developmental difficulties

One (1) out of three (3) people involved with this study presented with a developmental difficulty. The most frequent diagnoses are related to delays in language development, pervasive development disorders (such as autism), hyperactivity disorder and learning difficulties. Although the largest number of children with developmental difficulties falls under the Awash program (99), a surprisingly large number of people should be served under the Uschinichisuu program.

Table 5: Children and Youth with developmental difficulties

	Awash	Uschinichisuu	Total
Chisasibi	30	7	37
Eastmain	0	15	15
Mistissini	15	11	26
Nemaska	0	2	2
Ouje Bougoumou	0	1	1
Waskaganish	22	5	27
Waswanipi	18	5	23
Wemindji	12	3	15
Whapmagoostui	2	1	3
Total	99	40	139

The CBHSSJB offers very few services to children and youth with developmental difficulties. There are needs for culturally appropriate diagnostic, intervention and follow-up tools for most special needs.

It is expected that a large proportion of the young children suspected of having a “development delay” will later be diagnosed with a cognitive impairment, fetal alcohol syndrome disorder (FASD), severe behavioural disorder or others. Early stimulation is very important to maximize their capacity to learn. More support should be given to the Child Care Centres who are attempting to provide adequate stimulation to these children. Stimulation groups for mothers and children could also be implemented.

Speech Therapy services are needed for the large number of children and youth identified as being afflicted by language difficulties. Because of the lack of data related to the normal development of language in Cree speaking children and the complexity of

establishing an adequate diagnosis under these circumstances, it is expected that a larger number of people are afflicted by a language disorder but they remain unidentified.

At this point in time, the CSB provides consultation services to the school age children. Others are generally being referred to a Speech and Language Pathologist at the Montreal Children Hospital. These measures are expensive and do not offer any continuity of care.

There is also a lack of services for the children and youth who are facing learning difficulties. Occupational Therapists could provide assistance to some of these people but are often unable to secure the time necessary to provide services within the schools.

4.1.7 Services for people with cognitive impairments

Out of the forty-eight (48) people presenting with limited cognitive capacities, twenty-two (22) live in Chisasibi. They are almost all above nine (9) years of age (20/22). Mistissini also has a large number of youth with cognitive impairments (10).

Table 6: Children and Youth with cognitive impairments

	Awash	Uschinichisuu	Total
Chisasibi	2	20	22
Eastmain	1	0	1
Mistissini	0	10	10
Nemaska	0	0	0
Ouje Bougoumou	0	0	0
Waskaganish	1	3	4
Waswanipi	0	5	5
Wemindji	2	2	4
Whapmagoostui	0	2	2
Total	6	42	48

The CBHSSJB is currently not providing services to youth with cognitive limitations other than the services offered to the general population. These people are integrated into the regular school system and not much is available to them upon reaching the legal age to attend school. Often, these youth have a hard time complying with the school curriculum. There is a need for the CSB and CHB to clarify whose mandate it is to provide education/stimulation on daily living skills other than reading and writing. These youth need help to learn how to take care of themselves (e.g. getting dress, brushing their teeth, preparing a light meal), learn a trade, develop an understanding of money, etc.

In Chisasibi and Mistissini, there is a need to implement a daily program to teach young people with limited cognitive skills on the basics for independent living. This should include vocational training. Contrarily to what is currently done at the MSDC with the older population, this program should not solely aim at occupying/keeping busy the clients. They should learn the necessary daily skills, be assisted to find a meaningful purpose to life (e.g. a job) and be discharge from the program.

Often, young adults with limited cognitive capacities rely on their parents to function at home. The reality is that the caregivers are often aging and will not be available forever. It is important for people with limited cognitive capacities to learn how to live

independently. Supported living arrangements such as the services offered in supervised apartments should be implemented in Chisasibi and Mistissini. Supervised apartments could also be accessible to people with mental health difficulties and other adults in partial loss of autonomy.

4.1.8 Services for people with socio-emotional impairments

Some people are diagnosed with Foetal Alcohol Spectrum Disorder (FASD), severe behavioural disorder, anxiety disorder, oppositional disorder and other pathology of similar nature. In general, those diagnoses are made following observation of the person’s behaviour and functional capacities over time. They are generally not the results of a physiological test such as a blood test. For that reason, it is very likely that the actual number of people currently living with these diagnoses is higher than what was identified during the study.

Table 7: Children and Youth with socio-emotional difficulties

	Awash	Uschinichisuu	Total
Chisasibi	3	8	11
Eastmain	5	3	8
Mistissini	1	5	6
Nemaska	0	2	2
Ouje Bougoumou	0	2	2
Waskaganish	4	12	16
Waswanipi	1	5	6
Wemindji	0	4	4
Whapmagoostui	3	7	10
Total	17	48	65

The large amount of children and youth with special needs due to prenatal exposure to drugs and alcohol is alarming. Although entirely avoidable, prenatal exposure to drugs and alcohol causes severe developmental difficulties that are generally irreversible. Many of these children will face serious challenges that will impact on all aspects of their life. It is crucial to sensitise the population to the destructive impact of using drugs and alcohol and not taking active measures to prevent pregnancy. Waiting for the mothers to be pregnant to provide them with this information is too late. Protective measures must be in place at the time of the conception.

It is difficult to identify the number of children affected by prenatal drugs and alcohol exposure because they present with a wide variety of special needs that are not always related to drug and alcohol exposure. It is sometimes possible to identify children affected by Foetal Alcohol Spectrum Disorder but it is harder to establish a correlation with learning disabilities, behavioural disorders, limited cognitive capacities or difficulties to control emotions. For these reasons, the total number of children affected by the problem in Eeyou Istchee remains unknown. Services must be implemented to accurately diagnoses and help these children develop their full potential.

The reported number of children and youth presenting with behavioural difficulties is also of concern. Often, the families are largely affected by the challenges of caring for somebody who has difficulties controlling their moods and actions. The parents reported feeling isolated with the situation. These children often encounter difficulties in school. They may also be at high risk for juvenile delinquency. At this point in time, the CBHSSJB relies on the occasional visits of the psychologists to offer services to these children. It appears essential to provide regular services from Psycho-Educators because they are often experts at identifying solutions to modify behaviours. The services should be provided locally, and ideally available on a weekly basis. Moreover, consistency in the interventions from various care providers is crucial to limit the possibility for cleavage. Case Management is necessary to ensure congruity in the intervention plans of the various care providers (Teachers, Psycho-Educator, Parents, etc.).

4.1.9 Services for people with mental illnesses

The number of children and youth reported as being mentally challenged was very small during the population study (Total 11). It is believed that these numbers do not reflect the reality. Various factors may have contributed to these low numbers. Amongst others, the difficulty to establish a diagnosis of mental illnesses in children, discomfort of the parents regarding the diagnosis, misunderstanding of the distinction between mental illnesses and cognitive impairments and the presence of additional difficulties such as a learning disability might have influence the data.

Table 8: Children and Youth with mental illnesses

	Awash	Uschinichisuu	Total
Chisasibi	0	0	0
Eastmain	0	0	0
Mistissini	0	6	6
Nemaska	0	0	0
Ouje Bougoumou	0	0	0
Waskaganish	0	1	1
Waswanipi	1	3	4
Wemindji	0	0	0
Whapmagoostui	0	0	0
Total	1	10	11

At the CBHSSSJB, there is a need to clearly determine who should receive services from the Mental Health Department versus the Special Needs Department. This clarification would facilitate the identification of proper resources for each person in need.

A partnership with the Douglas Hospital ensures local psychiatric services to adults with mental illnesses. However, equivalent services are not available for young people facing similar challenges. There are growing needs for paediatric psychiatric services in Eeyou Istchee.

Care providers also made requests for help with older children who are using drugs and alcohol. Most resources to help people with addiction are geared for individuals who are of adult age. Treatment centres rarely accept people of less than 18 years of age. The necessity to identify services for that category of needs should be considered seriously. The longer the exposure to harmful substances, the harder it is to modify the unhealthy life habit and higher is the chance of negative impacts on the person's health and life.

4.1.10 Services for people with multiple handicaps

In most communities, there are some individuals who are suffering from multiple handicaps. Often these people experience a combination of physical illnesses combined with cognitive limitations and developmental delays. These children are often the ones who cannot efficiently be served within the community. Often, they receive more services from a specialized centre in an urban area. Making the choice to move outside of Eeyou Iscthee is an important decision that has repercussion on the entire family. In most cases, the families would prefer to stay in the community but feel forced to move because of the nature of their child's needs. In other cases, the child is placed under the care of another person, sometimes a stranger, away from his family, to attend a specialised program adapted to his/her needs in Gatineau, Hull or Montreal.

Table 9: Children and Youth with multiple handicaps

	Awash	Uschinichisuu	Total
Chisasibi	6	7	13
Eastmain	0	2	2
Mistissini	1	1	2
Nemaska	0	0	0
Ouje Bougoumou	0	0	0
Waskaganish	4	9	13
Waswanipi	3	8	11
Wemindji	0	3	3
Whapmagoostui	3	1	4
Total	17	31	48

It is expected that, in some cases, the improvement of the overall services provided to children and youth with special needs in Eeyou Istchee could prevent and/or delay the need for permanent departure from the communities. However, partnering between the various entities (CBHSSJB, CRA and CSB) is necessary to ensure that a holistic approach to care is used for each youth and that all aspects of the person's life are considered. Placement outside of the community should be a final resort, when everything else failed.

There is an inconsistency between the CBHSSJB and CSB concerning the compensation of expenses related to placement outside of the communities. Some amounts appear to be compensated by both entities simultaneously while others are not covered at all. There is

a need to develop an administrative level of communication between both entities as well as to clarify the relevant policies and procedures.

4.2 Cree School Board

The Cree School Board provides services to a large number of children and youth with special needs. When a diagnosis is established and the needs of the children are clarified, it is sometimes possible to receive additional funding from the Ministry of Education of Quebec (MEQ) to provide specific services. The funding varies depending on the code that is assigned to the child. It can be used to purchase specialized equipment for that child or to hire the necessary human resources to supervise him/her in order to facilitate his/her learning in a school setting. One hundred and eighteen (118) children of Eeyou Istchee are reported as being coded at the MEQ.

Table 10: Children and Youth with a code from MEQ

Community	Children with an MEQ code
Chisasibi	27
Eastmain	7
Mistissini	17
Nemaska	4
Ouje Bougoumou	2
Waskaganish	19
Waswanipi	17
Wemindji	16
Whapmagoostui	9
Total	118

Although it is generally easy to identify the children in need for additional services at the school, it appears to be much harder to acquire all the necessary information to establish a file in order to apply for the most needed funding. The documents to be presented may include a medical letter describing the diagnosis, report from psychological evaluation and/or letters from various specialists explaining the nature of the needs. An improved communication with the CBHSSJB would facilitate the process. It is believed that amongst the 516 children and youth with special needs in Eeyou Istchee, more than 118 would qualify for the additional funding. The importance of preserving confidentiality should not interfere with adequate provision of services. Most caregivers expressed

willingness to authorize transmission of information between the entities if it may imply better services for their child.

The MEQ establishes clear educational programs for all children and youth in Quebec. However, it is not always possible for children and youth with special needs to successfully complete each module. There is a need to identify alternate teaching strategies for some children with special needs. There is also a need to determine under which circumstances, the general academic knowledge (reading, writing, geography, mathematics, etc.) should be abandoned to focus more on skills necessary to function independently in life (self-care, personal safety, vocational training, etc.).

The CSB, maybe in collaboration with Cree Human Resources Development (CHRD), should also consider the possibilities to broaden the opportunities for vocational training, internships and on the job training. These measures would enlarge the working opportunities for people with cognitive limitations, learning disabilities and decrease attention span. In the current economic situation, these people are more likely to remain unemployed.

The caregivers who collaborated with the Population Study expressed the wish for the schools to improve the communication mechanisms between the classroom and the child's natural home (71 respondents). They often reported being unaware of the child Individual Educational Plan (IEP) as well as the basic curriculum outline according to the child's grade (77%). The caregivers also reported difficulties to transmit daily information to the teacher. Many caregivers contact the teacher directly in the classroom (during school hours) or at home to talk about the child's situation.

Another situation that preoccupied the caregivers was the uncertainty that their child safely commuted between the natural home and the school. In most communities, transportation by bus is available only to kindergarten to grade 2. Older children are expected to walk to school. Except for the fact that the communities are now getting bigger in size, this situation is adequate for most children and youth. However, for easily distractible children such as those presenting with attention deficits, behavioural difficulties and/or cognitive impairments this can be a hazardous journey (might get lost,

choose to not go to school, etc.). It is suggested to implement a system ensuring that parents are notified every morning for all unexpected absence from a child.

As mentioned earlier, the number of children and youth suffering from prenatal exposure to drugs and alcohol is alarming. The collaboration of the CSB would be very beneficial to teach future parents about the risks of exposing the unborn child to those harmful substances. These teaching should be part of the regular school curriculum. The School Nurse and Social Worker could probably greatly collaborate to this project.

Finally, the CSB appears to regularly rely on external consultants for professional expertise concerning children and youth with special needs. Over the last few years, the CBHSSJB largely widened the spectrum of professionals available locally. In some communities, it is now possible to access the services of Psycho-Educators, Physiotherapist and Occupational Therapists. In 2010, Speech Therapy will even become available in some communities. An increased partnership between the entities could mean better services for the children since these services are available locally. It is suggested to use that channel of services before networking and partnering with external resources.

4.3 Cree Regional Authority (CRA)

In general parents of children with special needs appear to be satisfied with the services provided at the Child Care Centres. Many children are benefiting from one-on-one stimulation provided by a Special Needs Educator. In some facilities the volume of children in need may be large enough to justify group interventions through an early stimulation program.

In most communities, there are parents, including foster parents, who would benefit from support to build their confidence in their parental skills. This could be done through parental workshops, brief seminars on specific subjects, weekly discussion group and activities involving the parents and children simultaneously.

Many parents commented on the fact that the lunch and after-school programs, operated under the CRA, could be improved to better serve children with special needs. It was suggested to develop a partnership with the schools to maintain the shadows in function, through the after school program, until the special needs children are being pick-up. The

use of the MSDC resources to create an after school program adapted to children with special needs was also suggested because the employees in place are perceived as already having the expertise to provide the necessary care.

4.4 Band Councils

The career opportunities for people with special needs appear to be lower than those available to the general population. Various governmental programs exist to encourage employers to hire people with disabilities. The Band Councils are encouraged to set the example by hiring people with special needs and by supporting local shops and stores in taking advantage of these programs.

Children and youth who rely on a cane, walker or wheelchair to be independent sometimes have difficulties accessing public buildings. Universal accessibility norms should be used when modifying or designing a building. Attention should also be given to elevators and access ramps because they are sometimes inexistent or out of order. Moreover, the potential build up of large amount of snow during the winter months should also be considered in the landscaping plans. Because people with limited mobility are at higher risk for falling, it is important to clear all entrances from snow.

The caregivers frequently repeated the need to implement free public transportation (71 respondents). As the communities are growing in size, it is becoming harder for people with mobility restriction to walk from place to place. As a result, social isolation amongst people with ambulatory difficulties may increase in frequency.

The progressive expansion of the communities over time also generated the need to review the current policy for transportation of school age children. At this point in time, only kindergarten to grade 2 students, as well as children with severe special needs, are granted services. However, in some communities, there are children and youth who live far from the school. The possibility to provide transportation to those who live outside of a certain radius (maybe 2 kilometres) should be considered. This measure might also help in decreasing the large flow of vehicles around the schools at various times of the day.

Many families would also largely appreciate if recreational programs facilitated the integration of people with special needs. For example, some communities could offer

swimming lessons geared specifically towards children with special needs. Summer camps could also provide shadows for special needs children or have groups exclusively for higher needs participants.

Finally, the Band Councils could probably collaborate with the CBHSSJB and the CSB in raising community awareness about the danger of using drugs and alcohol while being pregnant.

5. RECOMMENDATIONS

5.1 Cree Board of Health and Social Services of James Bay

5.1.1 General Services

1. A Case Manager must be assigned to each person with special needs. This person should lead the multidisciplinary intervention team. He/she should ensure that a holistic approach is used for the provision of services. He/she should act as a contact person for all issues concerning the client. He/she should ensure the transmission of information between the various care providers and between the CSB, CRA and CSB;
2. A protocol to exchange information between the CHB, CSB and CRA should be established;
3. The files of clients with special needs should be reviewed to ensure that they are receiving dental care similar to those offered to the general population;
4. Necessary measures should be taken to ensure that each person evacuated for a health emergency is escorted. This might include discussions with the people in charge of the Challenger (type of plane used for some medical evacuations).
5. Assign an employee to research governmental programs available for people with special needs and to assist community members in applying for these programs. When possible, allocations should first come from the governmental agencies. Only in case of ineligibility should the CBHSSJB compensate.

5.1.2 Cree Patient Services

1. Review the Policies and Procedures guiding the services provided by the Boarding Houses, mainly those related to the number of beds, food service and house rules.
2. Implement mechanisms, such as satisfaction surveys, to control the quality of the services provided at the Boarding Houses;
3. Review the Policies and Procedures guiding the choice of accommodation made for each client. The choice of accommodation should take into consideration factors such as the client's diagnosis, number of escorts, necessary equipment to care for the person, and need for extra space for personal hygiene care;
4. Clarify the protocol determining who is allowed to stay at the hotel, at CPS expenses. Consider offering an amount of money equivalent to the cost of a stay at the Boarding House, as a compensation for the parents who choose to stay at the hotel at their own expenses.
5. Review the Policies and Procedures guiding the attribution of one or more escorts;
6. Evaluate the need to develop services outside of the "escort" system for young adults who can function autonomously in their community but would need supervision and/or guidance in a large city.
7. Implement a mechanism to inform the clients of referrals made on their behalf (especially follow-ups) and give an approximate time frame for the appointment.
8. Improve the process of returning the consultation reports to the communities to ensure that the patients receive adequate physical and emotional follow-ups, especially if a new diagnosis was established.

5.1.3 Social Services

1. A mechanism should be implemented ensuring that all people newly diagnosed with a severely devastating illness are reported to Social Services. The diagnosed person and his/her immediate family should always be offered emotional support. In case of refusal of services, one or two additional attempts (3 to 6 months apart) should be made before closing the file;
2. Mechanisms should be implemented to break the isolation feeling of people with special needs and their families. This could be done through various means such as: linking newly diagnosed people and other consenting families who have been experiencing a similar problem for a longer period of time, providing information about electronic chat rooms (internet) for people with special needs and their families, as well as developing local support group;
3. All efforts should be made to establish a list of emergency sitters that could take charge of a child with special needs or his/her siblings in case of an emergency (such as medical evacuation of a family member);
4. A program could be implemented to educate and support young parents and first time parents before the birth of the child. This program could include prenatal classes, mentorship between an elder and the parents and/or use of technological aids (DVD, Internet) to learn more about how to care for a child;
5. Parental workshops should be offered locally. Basic advices related to every day issues such as establishment of a daily routine, healthy eating habits, discipline and the importance of daily physical activities should be addressed;
6. All efforts should be made to develop respite care facilities in each community. This project should not only involve identifying the physical space to welcome these children but also develop a stimulation program for the children and adequately train the employees;

7. Workers should be made aware of the various sources of funding available to people with special needs (federal government, provincial government, Societe de l'Assurance Automobile du Quebec, emploi Quebec, etc.). The forms should be readily available to them. The workers should be mandated to assist their client in completing the forms;
8. Social intervention plans should include identification of another legal guardian or caretaker in case of death or disability of the primary caretaker.

5.1.4 Multi Services Day Centres

1. The possibility to use the facility as well as the employees to implement activities geared to children and youth with special needs should be considered. This service would be more likely to be used after school hours, during school holidays and during the summer season;
2. The staff and facility could be used to run the after school program in a safe environment for children with special needs;
3. The staff and facility could be used to provide adapted extracurricular activities to young individuals with special needs;

5.1.5 Services for people with physical limitations

1. All efforts should be made to fill the positions of School Nurses. Waswanipi should be given priority considering the very large number of children and youth with physical limitations;
2. Occupational Therapy and Physiotherapy services should be available in all communities. Rehabilitation employees should be replaced during their sorties, which can add up to three (3) months per year.

5.1.6 Services for people with developmental difficulties

1. Services for people with developmental difficulties should not be only developed under Awash program but also under the Uschinichisuu program since 40% of the people in need fall under that age group;
2. Take necessary measures to ensure proper diagnosis of children and youth with special needs such as development of culturally appropriate assessment tools and implementation of assessment teams;
3. Develop Speech Therapy services in Eeyou Istchee instead of relying on external services;
4. Develop tools such as a bank of data that could be used to determine normality in language development for children using Cree as their First Language;
5. Hiring Occupational Therapists to work specifically with children facing learning disabilities in school should be considered, specially in communities presenting with a large number of children with developmental difficulties (Chisasibi (37), Waskaganish (27), Mistissini (26));
6. Develop specific services to offer early stimulation to preschool children suspected of developmental delays. This could be done in partnership with the Child Care Centres.

5.1.7 Services for people with cognitive impairments

1. It is recommended for the CSB and CBHSSJB to develop a common understanding of whose responsibility it is to teach young people with special needs the necessary skills that are not included in the regular school curriculum (e.g. activities of daily living, healthy eating, budgeting);
2. Daily stimulation programs should be implemented at least in Chisasibi and Mistissini. Although the MSDC building could be used for this purpose, the program should be different than what is currently done in those facilities. The goal should be to assist the participant in developing the necessary skills to function autonomously (including finding a job) and then discharge him/her from the program;
3. Supported living units, also known as supervised apartments, should be built in Chisasibi and Mistissini.

5.1.8 Services for people with socio-emotional impairments

1. The CBHSSJB should lead a massive campaign informing the general population of the dangers of exposing the unborn child to drugs and alcohol. This project could be done in partnership with the CSB;
2. An FASD diagnostic and intervention team should be implemented;
3. Interdisciplinary care plans touching on all aspects of these children's life must be implemented to ensure consistency amongst the care providers (e.g. parents, Teachers, Educators). Case management appears to be specifically important to implement with these children.
4. Develop small group activities, stimulation program and specialized summer camps for children with behaviour and learning difficulties to ensure continuous, adequate stimulation through the year (not only during school).

5.1.9 Services for people with mental illnesses

1. Clarify the criteria to receive services under the CBHSSJB Mental Health Program versus the Special Needs Program;
2. Develop local paediatric psychiatric services similar to the services provided to adults with mental illnesses;
3. Develop services for youth using drugs and alcohol.

5.1.10 Services for people with multiple handicaps

1. Because of its important impact on the person's life, placement outside of the community should be avoided/delayed for as long as adequate services can be provided locally. When possible, professional resources should be brought up to train local resources instead of bringing the local care provider down south for training. This would ensure that the intervention strategies could realistically be implemented within the community;
2. Communication between the CBHSSJB and CSB should be improved when determining who will cover the expenses of people receiving services outside of Eeyou Istchee. This would prevent duplication of services and ensure that all needs are addressed;

5.2 Cree School Board

1. Develop an improved partnership with the CBHSSJB to communicate information concerning children who are receiving services from both entities. Policies and procedures should ensure systematic transmission of diagnosis and professional reports. Protection of confidentiality should not interfere with provision of adequate services;
2. Alternate teaching strategies for children and youth with special needs should be identified. These could include thematic teaching, workshops, vocational training, internships and/or on the job supervision;
3. Guidelines should be revised/implemented to determine when and under which circumstances it becomes appropriate to diverge from the pre-established school

- curriculum to teach necessary life skills such as self-care, personal safety and appropriate social interactions;
4. Mechanisms to improve the communication with parents should be implemented. Amongst others, the IEP should always be presented, parents should be notified of their child absence from school and a procedure to exchange daily information between the school and the house should be identified. These strategies could consist of one annual meeting with the parents of all children with special needs, a phone call from the secretary when the parents did not leave a message explaining that their child will be absent and an agenda to be signed daily;
 5. Inclusion in the school curriculum of information concerning the devastating effect of using drugs and alcohol during pregnancy would help to raise community awareness. The School Nurse and Social Worker could be involved with this project.
 6. When professional services are necessary to provide additional services to a child with special needs, it is recommended to contact the CBHSSJB program Head (Awash or Uschinichisuu) or the Case Manager to determine if the resource is available locally before proceeding with external hiring. The use of local resources may translate into more regular, improved services for the child. Moreover, it may generate substantial financial savings for the CSB.

5.3 Cree Regional Authority

1. The possibility to group children with special needs to be provided with early stimulation program could be considered in some Child Care Centres with a large volume of users;
2. Services could be implemented to build the parents confidence in their parental skills. This is specifically important for parents of children with special needs, young parents and foster parents. It could be done using various strategies including weekend seminars, regular discussion groups and parent-child activities;

3. The lunch and after school programs could be modified to accommodate children with special needs. Possibilities of using the shadows from the school could be considered.

5.4 Band Councils

1. The design of public buildings should follow the universal accessibility norms;
2. The creation of public transportation, adapted for wheelchair users, should be considered;
3. The protocol guiding the provision of bus transportation to school age children should be revised. In addition to the age of the child, the distance between his home and the school should be considered;
4. When possible, recreational programs should be designed to accommodate children and youth with special needs. This could include spaces in summer camps for children with special needs and/or leisure activities that can accommodate for the unique nature of their needs;
5. Measures, such as road signs, posters or radio announcements could be implemented to raise public awareness about the dangers of using drugs and alcohol during the pregnancy.

CONCLUSION

The profile of the children and youth with special needs reported in this document, as well as the long list of recommendations to improve their quality of life can be overwhelming. However, it should be remembered that, at least, the situation is being discussed. Most likely, there were always people with special needs in Eeyou Istchee but providing them with specialized services was impossible.

By conducting a parent or caregiver's questionnaire through this Children and Special Needs Population Study, a significant step forward was made. Addressing the list of people with special needs, identifying the nature of their needs and more importantly proposing solutions may ease their life.

Moreover, the collaboration between the CBHSSJB, CSB and CRA, to this joint project is hopefully the step stone to a renewed partnership between the entities. Ultimately, it is the children and youth with special needs who could benefit the most by reaching their maximal potential in all aspects of their life. After all, as the public saying goes: "It takes a whole community to raise a child". Together, we can make the difference in the life of the special children of Eeyou Istchee and their families.

Appendix 1: Demographic Data

Age Group	0-19			20-64			65 and more			Total		
Year	90	00	08	90	00	08	90	00	08	90	00	08
Whapmagoostui	216	345	401	256	332	385	25	41	43	497	586	829
Chisasibi	1221	1412	1701	1132	1747	2044	125	141	179	2478	2888	3924
Wemindji	428	457	505	421	633	712	42	50	60	891	988	1277
Eastmain	190	260	263	188	287	323	31	26	44	409	476	630
Waskaganish	627	964	920	603	1075	992	63	67	65	1293	1471	1977
Nemaska	219	254	271	190	292	365	18	26	23	427	469	659
OujeBougoumou	----	288	320	----	298	337	---	19	19	---	501	676
Mistissini	1137	1221	1428	951	1545	1660	90	107	144	2178	2384	3232
Waswanipi	427	673	709	440	797	740	38	69	78	905	1017	1527
Total	4465	5874	6518	4181	7006	7558	432	546	655	9078	10780	14731

Appendix 2: Example of Diagnosis Under Each Category of Needs

Physical Needs

The conditions described under “Physical Needs” affect primarily the body of the person, for example:

Allergies	Juvenile rheumatoid arthritis
Arthritis	Kidney disease
Asthma	Migraines
Bronchitis (recurrent)	Mobility limitation
Cardiac problem	Motor delay
Chronic pain	Obesity
Congenital malformation	Ocular apraxia
Diabetes	Otitis media (recurrent)
Endocrine conditions	Physical disability
Epilepsy	Physical handicap
Failure to thrive	Quadriplegia
Headache (persistent)	Scoliosis
Hearing deficit	Spastic dysplegia
Heart condition	Spina bifida
Hemophilia	Strabismus
High blood pressure	Visual impairments
Hydrocephalus	
Hyperlipidemia	
Hypotonia	

Developmental Needs

The conditions under “developmental needs” are directly linked to an incomplete maturation of some aspects of the person, for example:

Asperger syndrome	Language deficits
Autism	Learning disabilities
Cree encephalopathy	Pervasive Development Disorder
Developmental delay	Speech impediment
Down syndrome	Trisomy 21
Fine motor delays	

Socio-emotional Needs

Socio-emotional needs are intimately related to the past or present environment into which the person evolves. The manifestation of these impairments would possibly be different in another setting or under different social norms. Examples of socio-emotional needs are:

Attention deficits	Hyperactivity
Behavioral disorder	Post-traumatic stress disorder
Emotional problem	Prenatal drug exposure
Fetal Alcohol Syndrome	Social Maladaptation

Cognitive Needs

Cognitive needs are due to intellectual limitation that affects the person’s capacity to learn and answer his/her basic needs autonomously.

Cognitive disorder	Mental Retardation
Down Syndrome	Microcephaly
Low IQ	Trisomy 21
Macrocephaly	

Mental Needs

Under “mental needs” are grouped conditions that affect the person’s capacity to control his/her emotions, to interact socially, and/or to perceive themselves and others:

Anorexia	Eating disorders
Anxiety disorder	Psychosis
Bipolar disorder	Schizophrenia
Bulimia	Suicidal ideation
Depressive disorder	

Multiple Needs

Under “Multiple Needs” category are listed conditions that largely impact on more than one (1) aspect of a person’s life. Occasionally, the needs of some people were considered “multiple” due to the severity of the symptoms in that person’s life. For another person with the same diagnosis but less severely affected by the disease, the needs might have been listed under another category. Examples of diagnosis that are likely to be considered under “multiple needs” include:

Cerebral Palsy	Severe Behavioural disorder
Foetal alcohol syndrome	Spina Bifida
Quadriplegia	