



REGIONAL PORTRAIT

OF THE SPECIAL NEEDS SITUATION
FOR THE FIRST NATIONS
OF QUEBEC CLIENTELE
BETWEEN THE AGES
OF 0 TO 6 YEARS

SEPTEMBER
2008
FNQLHSSC

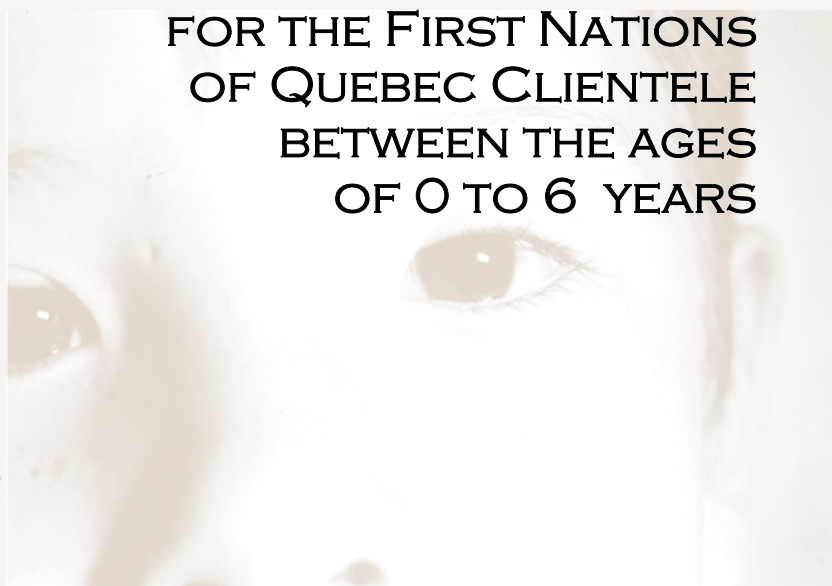


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Highlights

- Approximately 83% of the respondents stated that their service or program has children who have special needs of which 256 children have been registered.
- 65% of the children who have special needs have not been diagnosed. Without a diagnosis, it is difficult to obtain assistance and have access to support measures that are adapted to the needs of the child as well as their immediate entourage.
- Even though they can be the main diagnosis, language and learning problems and developmental delays are the types of special needs that are the most often identified. On the other hand, they can also indicate a group of troubles in the case of a main diagnosis.
- 65,2% of the employees who work directly with children ages 0-6 years do not have any training that is specific to early childhood development.
- Knowing that integration measures intended for children who have special needs aim to facilitate access to the services that they require, 64% of the respondents stated that their service or program does not have an integration policy to address children who have special needs.
- 49% of the respondents stated that the equipment and layout of their service or program is not adapted to provide for children who have special needs.
- The two professional resources that are the most accessible in the communities are nurses (88%) and social workers (85%).
- Ergotherapists (53%), speech therapists (51%), audiologists (51%), physiotherapists (51%) as well as specialized physicians (47%) represent approximately half of the professional resources that must be accessed outside of the communities.
- For those who live in isolated regions, the specialized services that must be accessed outside of the community become difficult to obtain either because of the expensive transportation costs and/or the long waiting list to meet a specialist.

1. INTRODUCTION

1.1 Background

The data on the health of First Nations children who are less than six years of age remains very limited and virtually unavailable. However, recent data suggests that investing in the first six years of a child's life can have a direct impact on his/her future health and well-being. These investments are even more important for children who have special needs. These children require services and care that are much more specialised to foster their optimal development, because:

- ✚ They are gifted with exceptional skills and talents;
- ✚ They suffer from physical, sensorial, cognitive and/or learning problems;
- ✚ They suffer from mental health problems;
- ✚ They have problems that are related to social, cultural, linguistic and/or family-based factors.

The problems that are related to early childhood health are many and are not screened in a correct or timely manner. Inaccessibility to adequate services prevents children from receiving the specific and required services that they need during the first six years of their lives. To further complicate the issue, parenting skills are often lacking and prevent the parents from identifying the special needs of their children.

The health of the children is at the heart of First Nations' concerns. In December of 2006, the Assembly of First Nations called upon the services of experts who are capable of carrying out a national-level research on the First Nations children who have special needs. The objective was to collect data on the special needs in twenty (20) First Nations communities across Canada.

Furthermore, the FNQLHSSC's mission consists of improving the physical, mental, emotional and spiritual well-being of First Nations and Inuit individuals, families and communities while respecting their culture and local autonomy. The FNQLHSSC is a regional resource that is currently expanding into the research domain for the First Nations of Quebec. The organisation has undertaken many research projects that are now considered successful models.

In March of 2007, the FNQLHSSC examined this issue and undertook steps to gather and study the most recent data in terms of special needs among the First Nations of Quebec. The creation of an additional position in the FNQLHSSC early childhood sector was appropriate for the development of this exercise which consisted of establishing the regional portrait of the situation in terms of special needs among the First Nations early childhood.

It is only recently that the Assembly of First Nations has re-established their research activities on the First Nations children who have special needs. A study is currently underway and since the FNQLHSC sits on the National Committee on Special Needs, the organisation will contribute to the provision of regional data that is gathered at this table.

This regional portrait presents a considerable amount of information that will serve to better understand the current situation among the children of the First Nations of Quebec who have special needs as well as to identify the priorities that must be addressed next to improve the health and well-being of our children.

1.2 Objectives

Investing in the health of the children is recognised as one of the priorities upon which there was a unanimous agreement on behalf of the First Nations interveners and representatives. The lack of action with respect to the deterioration of the health of the children is catastrophic for the future of the First Nations peoples. The health of the children stems from the historical and collective responsibility of all of the players whether they are from the social, government, First Nations leadership or family milieus.

In their **2007-2017 Blueprint**, the FNQLHSSC identifies various intervention focus areas to be prioritised with respect to choices for actions to undertake such as creating specialised services for children with special needs:

- ✚ Implement early screening into the early childhood services in order to avoid the late screening of children who have special needs, as is often the case;
- ✚ Establish specialised programs and services in close proximity to the communities to avoid the need for the children to leave their communities in order to access specialised services, which are often not adapted to their needs or their culture.

Consequently, the main objective of this project is to develop a regional portrait of the situation in terms of special needs for the First Nations of Quebec clientele between the ages of 0 to 6 years. This project will enable us to obtain specific information on the special needs children under six years of age, which will be used to:

- ✚ Provide information on the needs and realities experienced in the communities regarding the children who have special needs among the First Nations of Quebec;
- ✚ Establish a decision-making process regarding an action plan on special needs for the communities;
- ✚ Help the First Nations communities to obtain additional resources to support the development of children who have special needs.

2. METHODOLOGY

2.1 Questionnaire

In January of 2008, a questionnaire was developed by the FNQLHSSC's Early Childhood sector in order to collect recent data on the current situation of the First Nations of Quebec children who are less than six years of age and have special needs. The request for proposals (RFP) process that was developed by the Assembly of First Nations regarding the Special Needs Research served as a reference for its development. The questionnaire focussed on dimensions that reflect criteria that fostered:

- ✚ The description of the clientele;
- ✚ The description of the service;
- ✚ Access to resources;
- ✚ Identification of the respondent;
- ✚ Comments.

The questionnaire was intended for people who work with children between the ages of 0 to 6 years in the First Nations of Quebec communities and was based on the participation of the managers of the various services intended for the First Nations of Quebec early childhood. Various types of respondents were liable to fill out the questionnaire such as the director of a service, child care service coordinator, Head Start coordinator, early childhood centre coordinator, social worker, nurse or teacher.

The questionnaire could be completed alone or as a team.

Before its use, the questionnaire was pilot tested among the members of the First Nations Early Childhood Regional Advisory Committee (FNECRAC), which brings together professionals that are selected based on their expertise and experience in the First Nations early childhood field and tasked with measuring the efficiency of the FNQLSHSSC Early Childhood sector programs to ensure that they address the needs and realities of the communities.

Participation was on a voluntary basis. However, we stressed the importance of gathering community-based information in order to establish a portrait that is as accurate as possible and representative of the actual needs and realities.

It was specified that the transmitted information would be processed in a confidential manner and would only serve for the purposes of this current evaluation. Once the report is finalised, all of the questionnaires will be stored in a secure fashion at the FNQLHSSC and then destroyed after a period of three (3) years.

The translation of the questionnaire into the two official languages was necessary in order to reach all of the communities of the First Nations of Quebec.

2.2 Population and final sampling

In order to establish a portrait that is as representative of the reality as possible, the questionnaire was sent out to all of the First Nations of Quebec communities, for a total of thirty (30) communities, with the exception of the Cree and Inuit. We have collected a sampling of approximately 130 services or programs based on the mailing lists of the various sectors of the FNQLHSSC – such as the social services, health and early childhood sectors. Approximately six (6) copies were sent out to the various sectors of a given community. A covering letter was addressed to the directors of the

aforementioned services accompanied by a questionnaire. The questionnaire could be filled out individually or as a team for a service or program and could also represent one or many services or programs.

On the other hand, the project also focused on First Nations children under six years of age living outside of the communities. To that end, questionnaires were sent out to the directors of early childhood centres in urban areas that provide services to First Nations children. A copy, accompanied with a covering letter for the director, was sent out to Val d'Or, La Tuque, Quebec and Montréal for a total of four (4) early childhood centres in urban areas.

The following map presents the final sampling in terms of the communities that filled out the questionnaire.

Map 1: The participating communities



In total, fifty-nine (59) respondents returned their filled out questionnaires representing eighty-six (86) types of services or programs stemming from the communities as well as the early childhood centres in urban areas.

Table 1: Breakdown of the number of questionnaires filled out by the communities.

Nation	Communities	Number of questionnaires received	Number of responding programs or services
Abenaki	Odanak	2	2
	Wôlinak	1	2
Algonquin	Eagle Village-Kipawa	1	1
	Kitcisakik	2	3
	Kitigan Zibi	1	2
	Lac Simon	1	1
	Pikogan	3	3
	Timiskaming	3	3
	Winneway/Long Point	1	2
Atikamekw	Manawan	2	2
	Opitciwan	2	4
	Wemotaci	3	5
Huron/Wendat	Wendake	3	3
Innu	Bestiamites	2	2
	Ekuanitshit	1	2
	Essipit	1	5
	Mashteuiatsh	4	4
	Matimekush-Lac-John	2	2
	Natashquan	3	10
	Pakua Shipi	2	2
	Uashat mak Mani-Utenam	2	2
	Uashat	1	1
	Mani-Utenam	1	1
	Unamen Shipu	2	3
	Mi'gmaq	Gesgapegiag	2
Listuguj		3	3
Mohawk	Kahnawake	1	3
	Kanesatake	3	4
Naskapis	Kawawachikamach	1	2
Total:	28	56	83

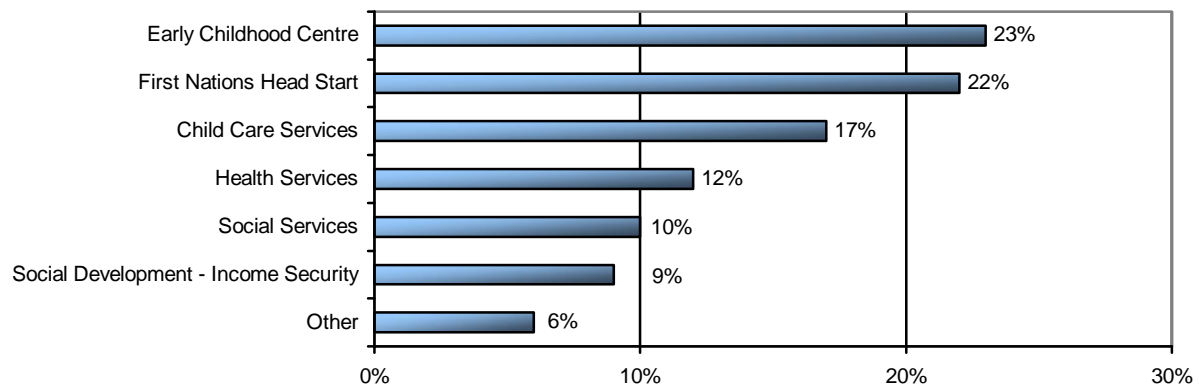
Table 2: Breakdown of the number of questionnaires completed by the early childhood centres in urban areas.

City	Number of questionnaires received	Number of sectors or programs that responded
La Tuque	1	1
Val d'Or	1	1
Québec	1	1
Total:	3	3

2.2.1 Types of services or programs

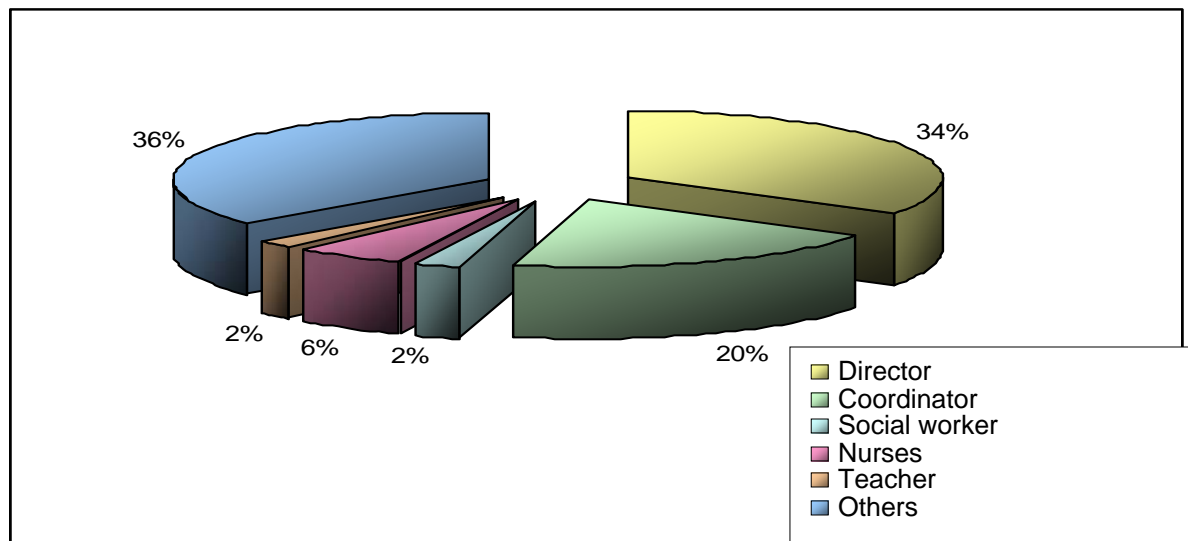
As illustrated in the following graph, the services or programs that are most represented are the early childhood centres (23%) and the First Nations Head Start programs (22%).

Graph 1: Percentage of the type of service or program represented among the respondents.



According to graph 2, the employees that hold management positions represent 34% of the total sampling. Among the other respondents representing 36% of the sampling, there were employees that held positions such as directors, educational advisors, assistant directors, social assistance workers, sector directors, early childhood educators, department heads, human relations agents, social workers, program agents and consultants.

Graph 2: Percentage of respondents represented.



2.3 Data collection

The questionnaires were sent out by mail in the beginning of February of 2008 accompanied by a covering letter addressed to the directors of each service. The respondents had until February 15th to fill them out and then return them to us.

In order to facilitate the data collection process, the person in charge of this project who was available to answer the community questions and ensure a follow-up with regards to the questionnaires fifteen (15) days after having sent them out, contacted the service directors during the first two weeks of March of 2008. The person in charge ensured that the questionnaires were received by each sector and then provided encouragement so that they could be quickly returned. Once the questionnaire was completed, the respondents could return it by fax or by email to the contact information that was provided. The last questionnaires were received by April 15, 2008. The data collection took place over a three-month period.

2.4 Data entry and analysis

Once the data collection phase was completed, the data entry process was carried out through the creation of a data base that was developed with *Microsoft Office InfoPath 2003*. In order to perform the data analysis and interpretation, it was necessary to then export the data to *Microsoft Office Excel*.

Once the data entry was completed, all of the questionnaires were stored in a secure environment at the FNQLHSSC to be destroyed after a period of three (3) years.

This portrait respects the Research Protocol that was developed by the Assembly of First Nations of Quebec and Labrador (AFNQL) that is based on the principles of Ownership, Control, Access and Possession (OCAP).

2.5 Limitations of the data collection

Despite all of the efforts deployed to minimise the errors and prejudices that could arise in the framework of this type of exercise, this project is not exempt from them.

This portrait does not pretend to provide exhaustive data concerning First Nations of Quebec children who have special needs. The data collected cannot be generalised. Therefore, the results presented in this portrait cannot be representative of all of the communities of the First Nations of Quebec.

Nonetheless, the presented results establish a first regional portrait on the situation in terms of the special needs of the clientele between the ages of 0 to 6 years among the First Nations of Quebec. This portrait could eventually serve as a reference document for more in-depth complementary researches – depending on the need.

The FNQLHSSC has sent out the questionnaire among the various respondents in the communities along with the related instructions. To that end, a community could receive up to six questionnaires. It is possible that there is an over-representation of children with special needs because of the possibility that various sectors could include a given child with special needs more than once.

Moreover, the respondents were solicited to fill out the questionnaire; given the fact that the respondents were free to fill out the questionnaire to the best of their ability - the possibility exists for biased interpretation, errors in the answers and a higher rate of non-response.

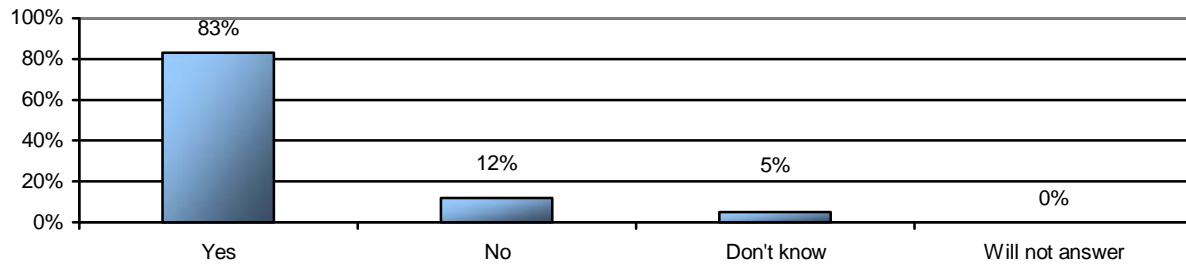
Finally, the FNQLHSSC had to face a few problems that had to be dealt with all throughout the process. Indeed, for reasons related to the end of the fiscal year, the response time that was given to each of the respondents was rather limited. This situation had repercussions on deadlines that weren't met and the response rate on behalf of the respondents.

3. RESULTS

3.1. Description of the clientele

The following graph illustrates that 83% of the respondents indicate that their service or program provides services to children with special needs.

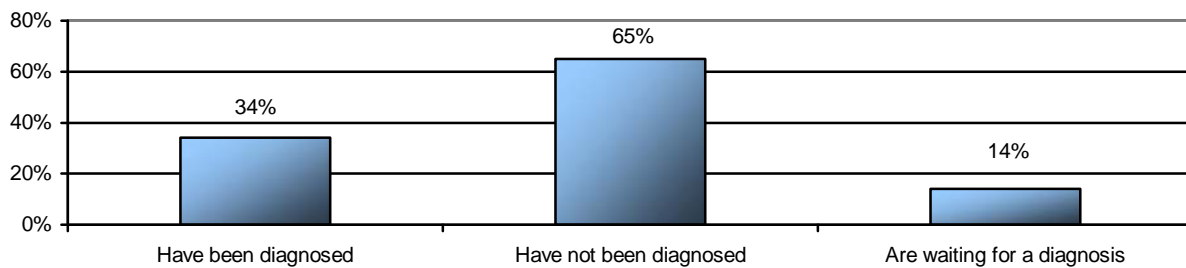
Graph 3: Percentage of respondents who have children with special needs.



The data collected in question CLI1.1 indicates that 256 children who have special needs are listed within the 86 various services or programs that are represented.

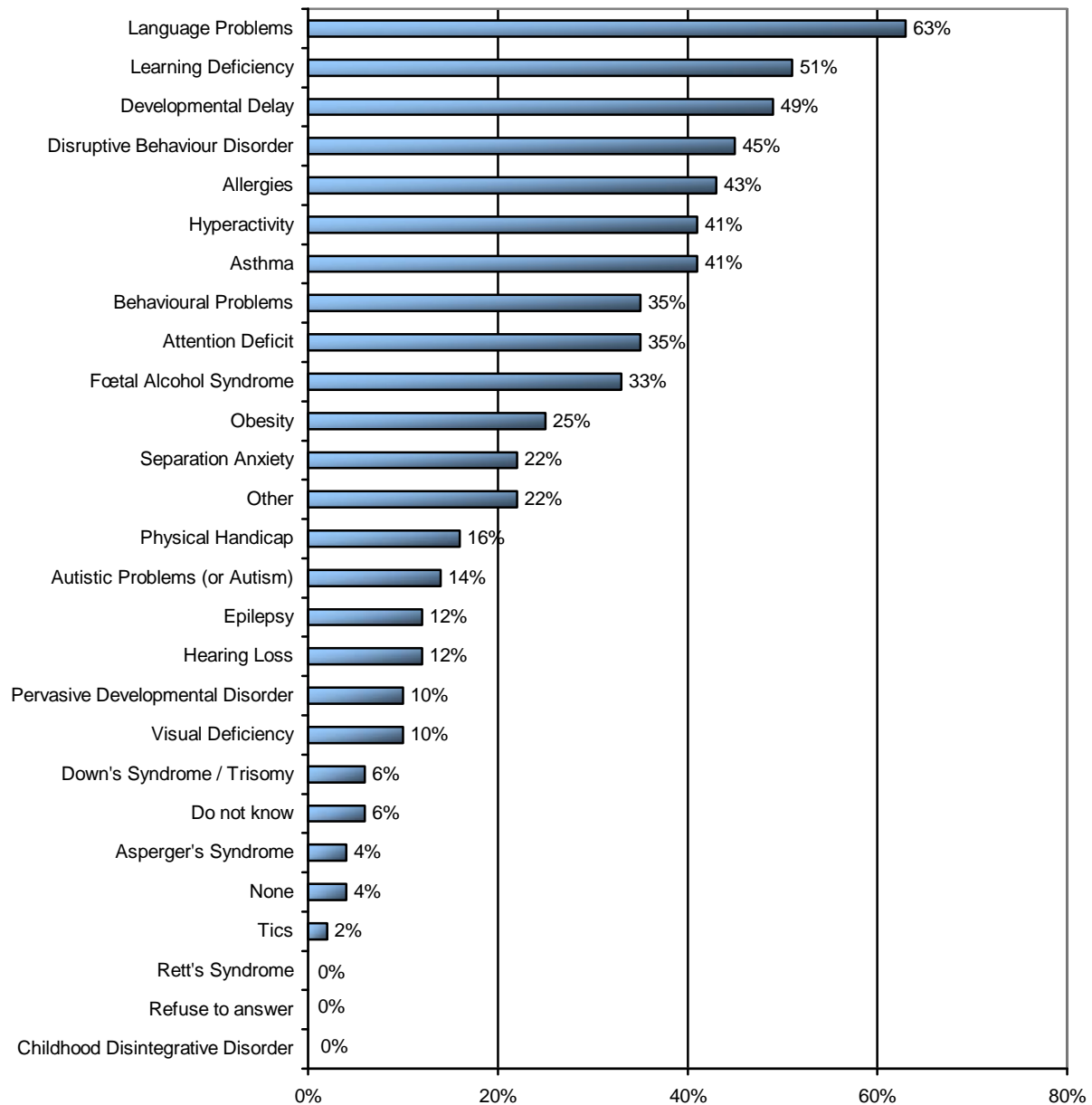
As indicated in the following graph, 34% of the children who have special needs have been diagnosed compared to 65% of them who haven't. Moreover, 14% of the children are waiting for an evaluation. Please note that the total surpasses 100% because some of the respondents placed a child into more than one category.

Graph 4: Characteristics of the listed children who have special needs.



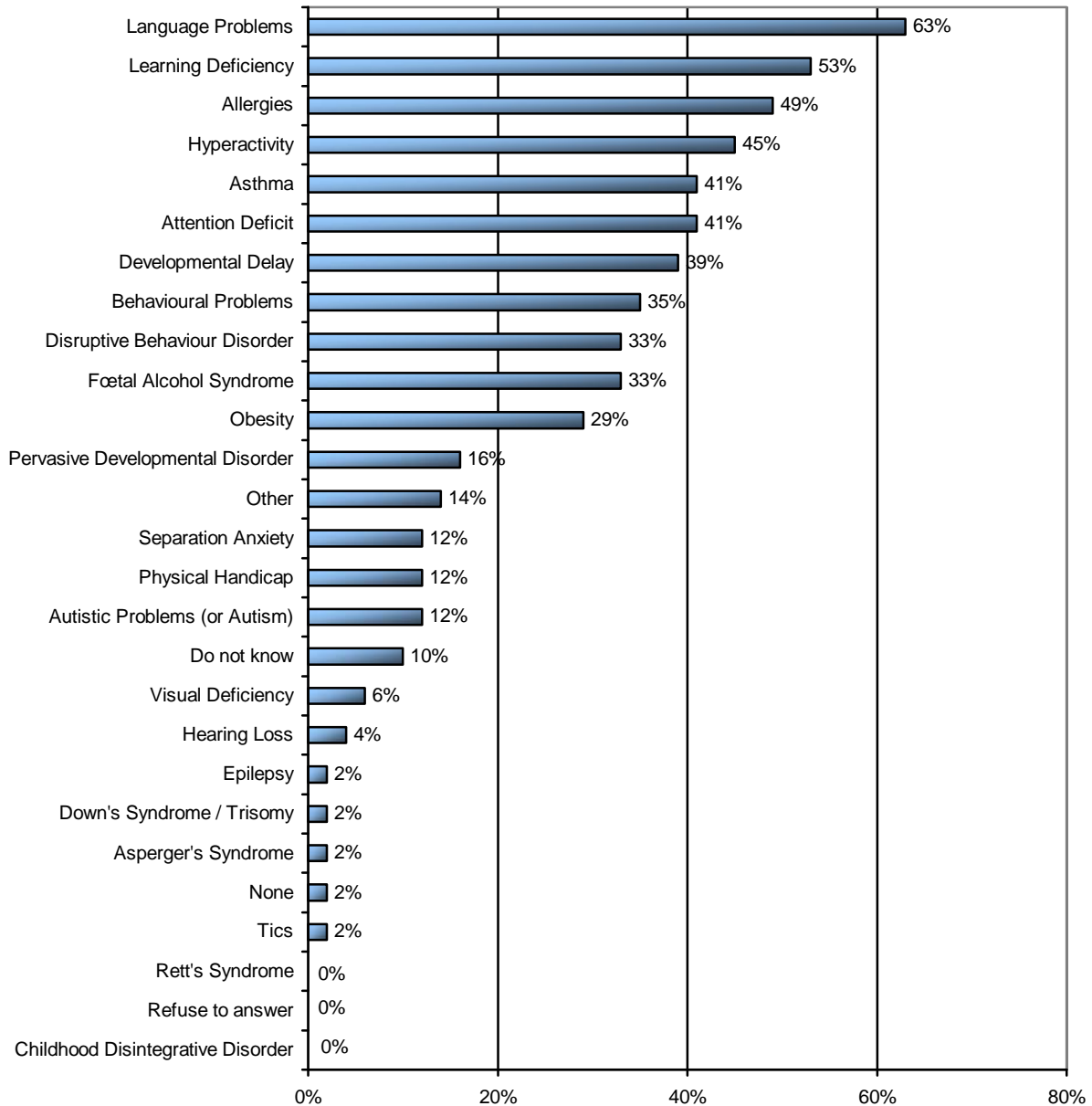
Among the respondents who stated that their service or program includes 83% of children who have special needs, graph 5 indicates that language issues, learning deficiencies and developmental delays are currently the type of special needs that are the most prevalent.

Graph 5: Percentage of the type of special needs identified within the services or programs.



Graph 6 indicates that language problems, learning deficiencies and allergies are the types of special needs that were most commonly identified in the past few years within the services or programs.

Graph 6: Percentage of the type of special needs identified over the past few years within the service or programs.

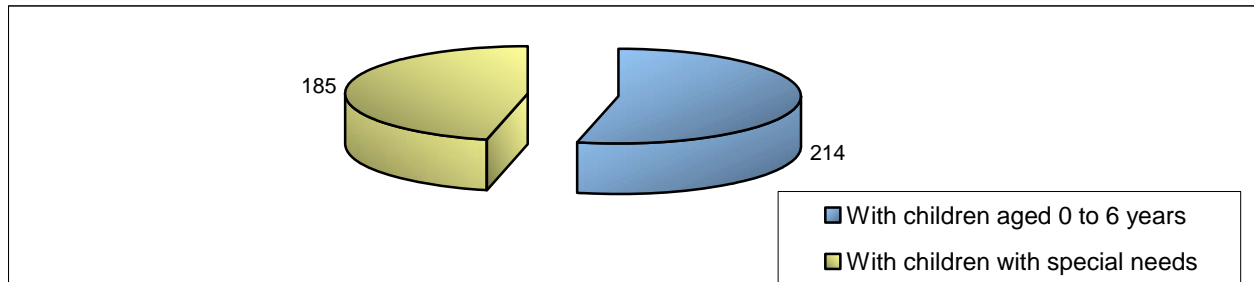


3.2. Description of the service

3.2.1 Human resources

According to the 86 types of represented services or programs, 399 employees work directly with the children between the ages of 0 to 6 years. Among them, 185 work with children who have special needs, which represents 46% of all of the employees.

Graph 7: Number of employees who work directly with the children

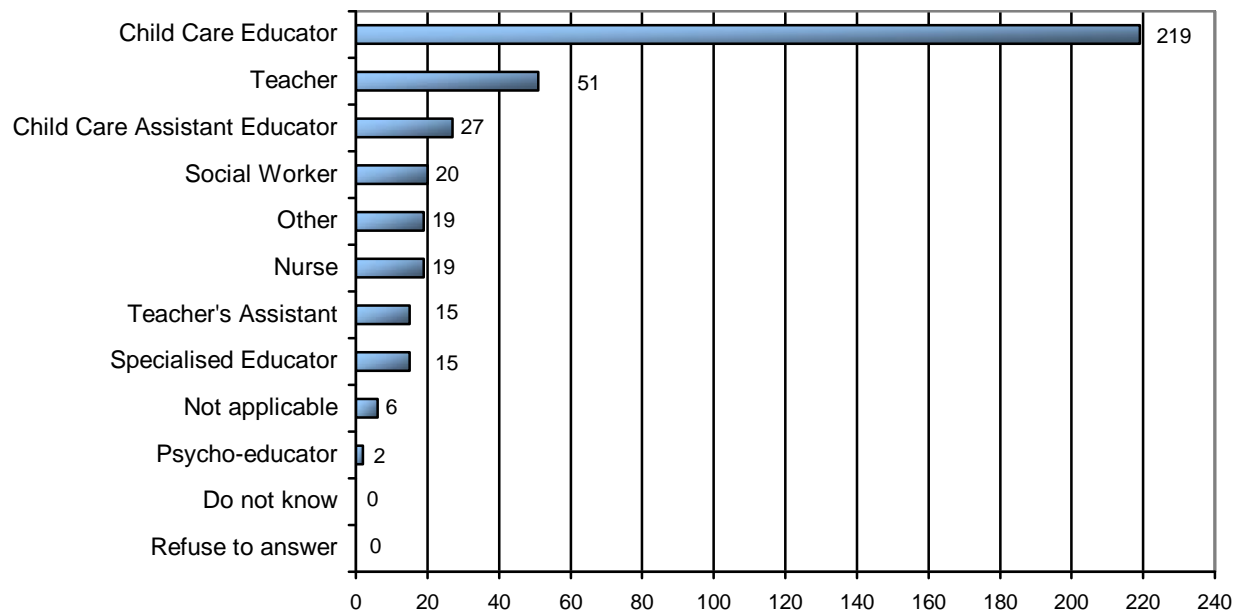


n= 399 employees

Graph 8 indicates that the child care educators are the professionals who are the most represented within the type of services and programs thereby representing 54.9% of the 399 employees who work directly with the children.

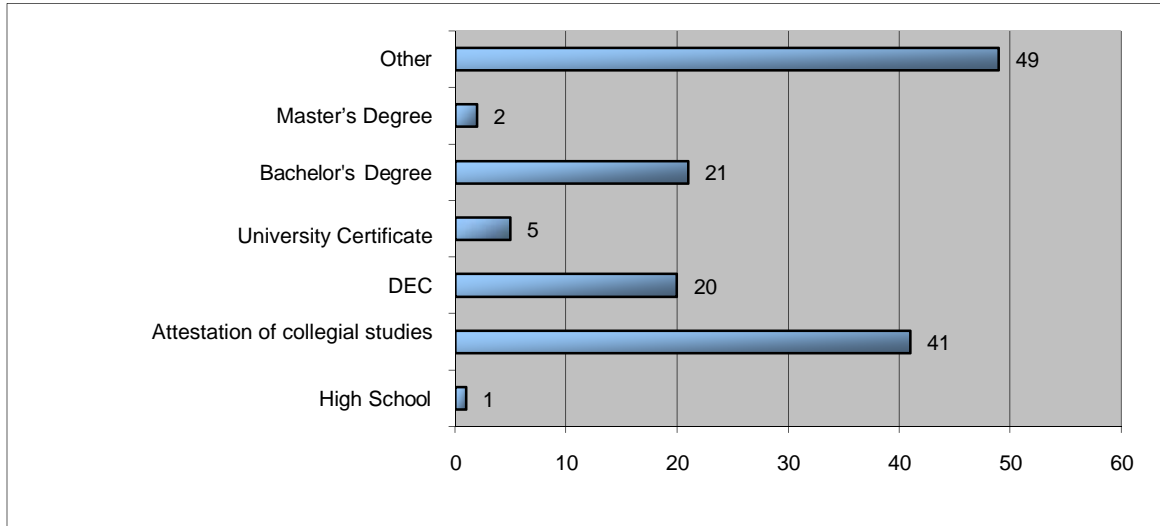
Among the listed 19 others, there are workers who occupy the following positions: physician, educational advisor, cook, resource teacher, psychologist, nutritionist, dietician, speech therapist, language instructor, physiotherapist, dental hygienist, support worker for children with physical handicaps, social worker and development agent.

Graph 8: Number of positions held by employees who work directly with teachers.

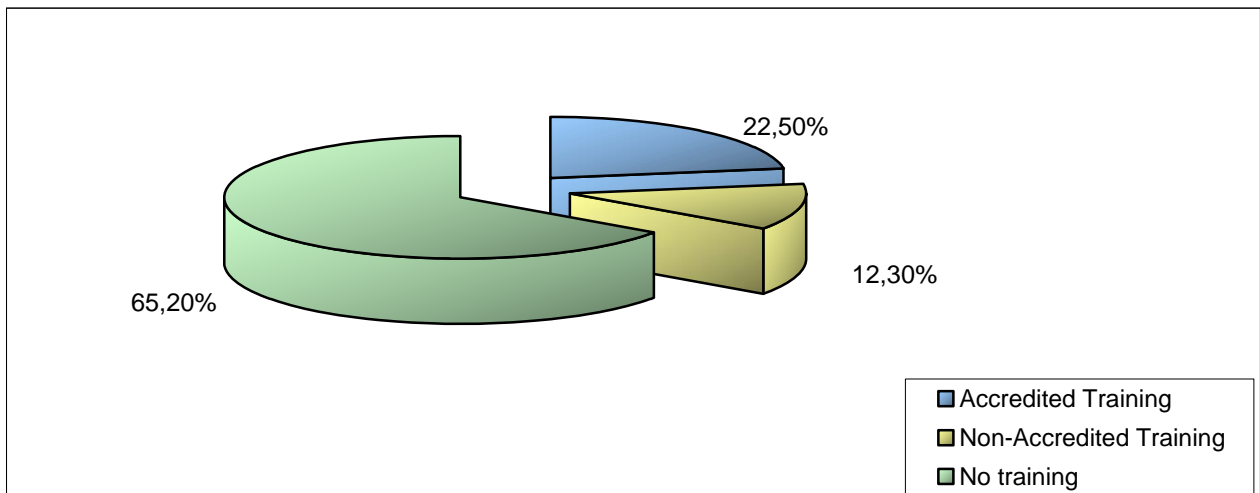


Graphs 9 and 10 indicate that, among the 399 listed employees, 61 have college-level training. In total, 90 employees have received accredited training, which represents 22.5%. The 49 other employees have received a non-accredited training that is specific to early childhood, which represents 12.3%. However, 65.2% of the employees who work directly with the children between the ages of 0-6 years do not have any training that is specific to early childhood development.

Graph 9: Number of trainings completed that are specific to early childhood development.

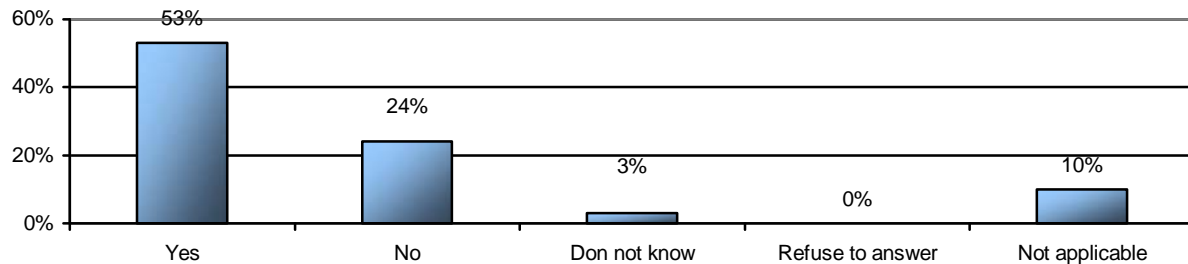


Graph 10: Percentage of employees who have received training that is specific to early childhood development.



The following graph illustrates that 53% of the respondents offer professional development training that is specific to early childhood to the employees of their service or program who work with this clientele. It must be noted that 24% of the respondents do not provide early childhood specific professional development training to the employees who work in their service or program.

Graph 11: Percentage of respondents who provide early childhood specific professional development activities to the employees in their service or program.

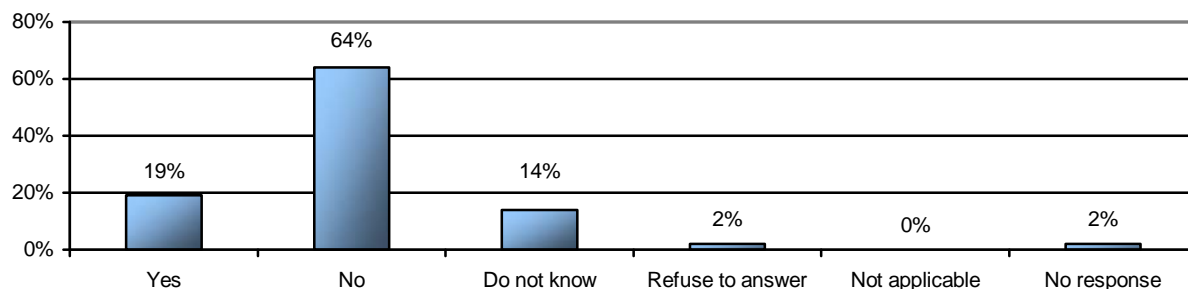


According to the respondents, the professional development activities that are generally provided to the employees are either given by the FNQLHSSC, the MFA or by the CJ and concern programs such as the educational program, Brighter Futures program, the “*Agir en milieu de garde*” program, Nobody’s Perfect program, and the “*Accueillir la petite enfance*” program. The professional development activities are on various subjects such as: child mental health, allergies, multi-age education, first aid courses, the relationship bond, Foetal Alcohol Syndrome, children and mourning, language deficiencies, nutrition, paediatric physical examination, childhood discipline, behavioural problems and sexual education among young children.

3.2.2 Tools

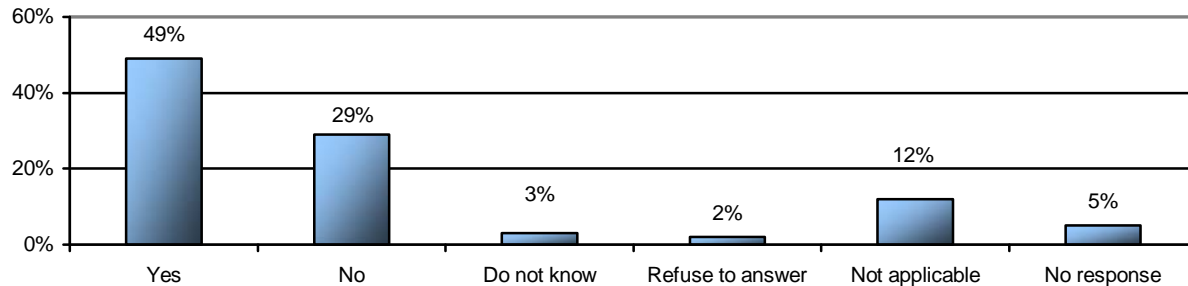
According to graph 12, 19% of the respondents indicated that their service or program is equipped with an integration policy intended for children who have special needs compared to 64% who do not have one.

Graph 12: Percentage of the respondents who are equipped with an integration policy for children who have special needs.



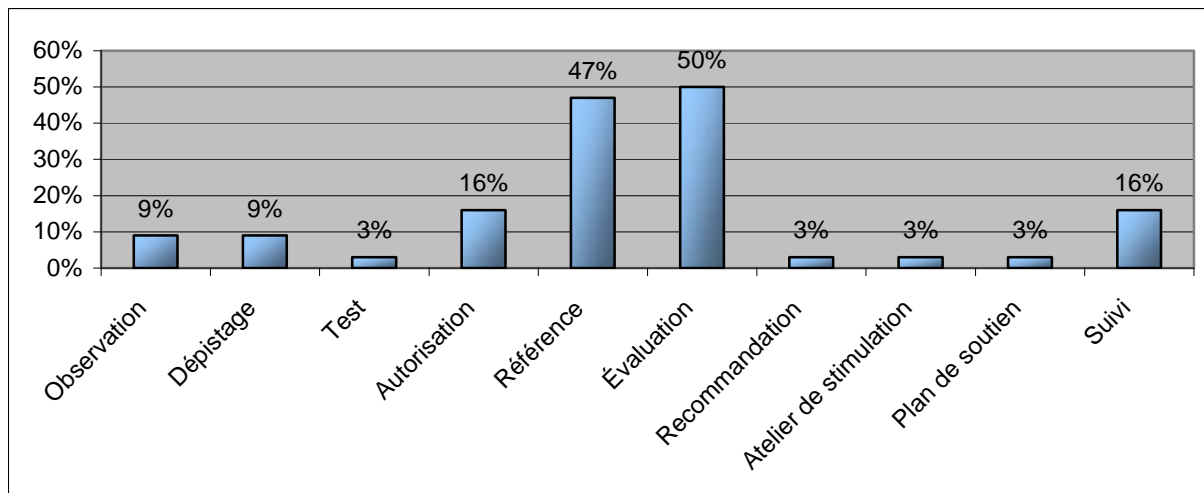
Graph 13 indicates that almost half of the respondents (49%) have stated that the children in their service or program are the object of a professional evaluation to determine if they have special needs. However, 29% of the respondents have indicated the contrary.

Graph 13: Percentage of the respondents who possess professional evaluation services to determine if the children have special needs.



As for the respondents who answered “yes” to this question, we interrogated them as to the way in which the evaluation procedures were used. The respondents reported activities that were carried out within their service or program to determine if the children have special needs. As is indicated by graph 14, almost half of the activities delivered to children who have special needs are the object of a referral¹ and an evaluation². Note that the total exceeds 100% because some respondents declared more than one activity provided to children who have special needs within their service or program. However, the activities mentioned are reported by a few respondents.

Graph 14: Activities declared by the respondents to determine if the children have special needs (%)

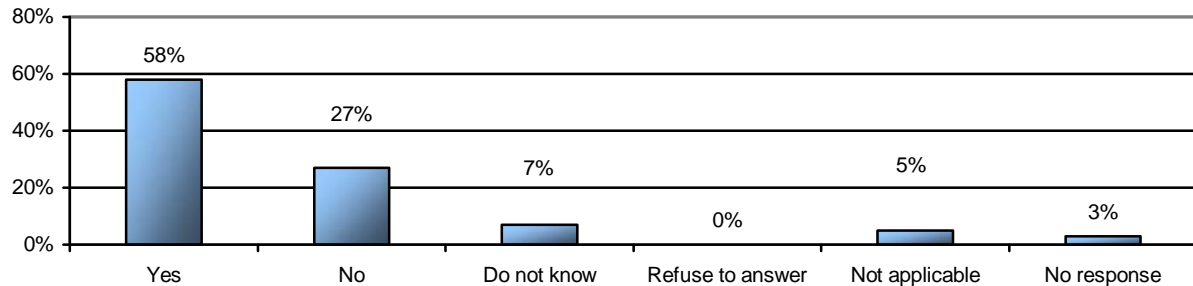


¹ Referral to other services such as a clinic, hospital and youth protection or specialised services such as speech therapist, audiologist, ergotherapist, physician, nurse, paediatrician, child psychologist and psycho-educator.

² Evaluation performed by psychiatrist, child psychologist, neuro-psychologist, ortho-paediatrician, speech therapist, psycho-educator, physician and specialised educator.

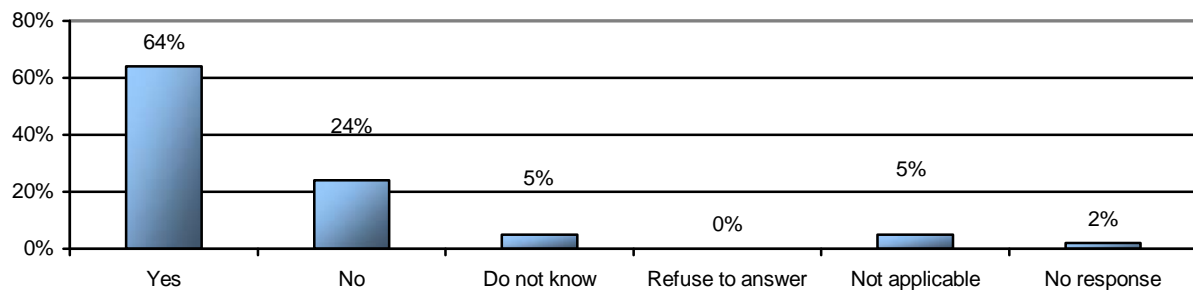
Graph 15 indicates that 58% of the respondents maintain that their service or program has the capacity to organise a support plan for children with special needs compared to 27% who are not capable.

Graph 15: Percentage of respondents who organise a support plan for children who have special needs.



Among the 59 respondents, 64% of them affirm that their service or program has the capacity to coordinate support activities for children who have special needs, as illustrated by the following graph.

Graph 16: Percentage of respondents who coordinate support activities for children who have special needs.



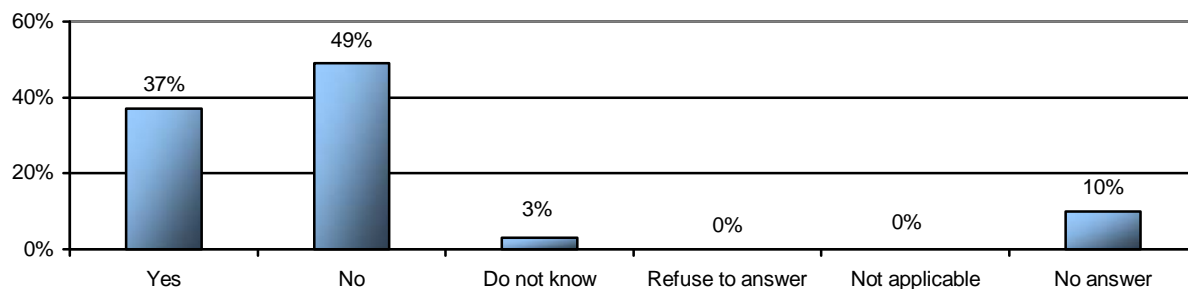
For question SER2.2.5, we asked the respondents to list the screening and/or evaluation tools used by their service or program for children who have special needs. The respondents reported a few programs such as the First Nations Head Start program (FNHS), the *Parcours d'enfant* and the *Programme d'Aide Personnelle Familiale et Communautaire* (PAPFC) in addition to the following screening and/or evaluation tools:

- *Guide Portage d'intervention précoce;*
- *Inventaire du développement de l'enfant entre 0-7 ans;*
- Ages & Stages Questionnaires and new ASQ: Socio-Emotional;
- Assessment, Evaluation and Programming System for Infants and Children (AEPS);
- Diagnostic Inventory for Screening Children;
- Mullen Scales of Early Learning: AGS Edition;
- Checklist for Autism in Toddlers (CHAT);
- *Grille d'observation des comportements;*
- *Grille diagnostique. Discas;*
- Nipissing District Developmental Screen;
- Woodcock-Johnson Battery--Third Edition (WJ III);
- The Connors Rating Scale - Revised (CRS-R);
- PDMS-2 (Peabody Developmental Motor Scales - Second Edition);
- Social Competence and Behaviour Evaluation (SCBE);
- *Évaluation Grille Ballon;*
- *Echelle de développement Harvey;*
- Allergies test;
- Blood test.

3.2.3 Equipment and Layout

When the respondents were asked about the equipment and layout of their service, 49% of them stated that the equipment and layout of their service or program is not adapted to the needs of children with special needs – as is indicated by the following graph. Some of them described the difficulties encountered such as the lack of equipment and materials recommended by specialised professionals as anticipated in the intervention plan or the impossibility for a child in a wheelchair to access the lunch room situated on the lower level of the establishment.

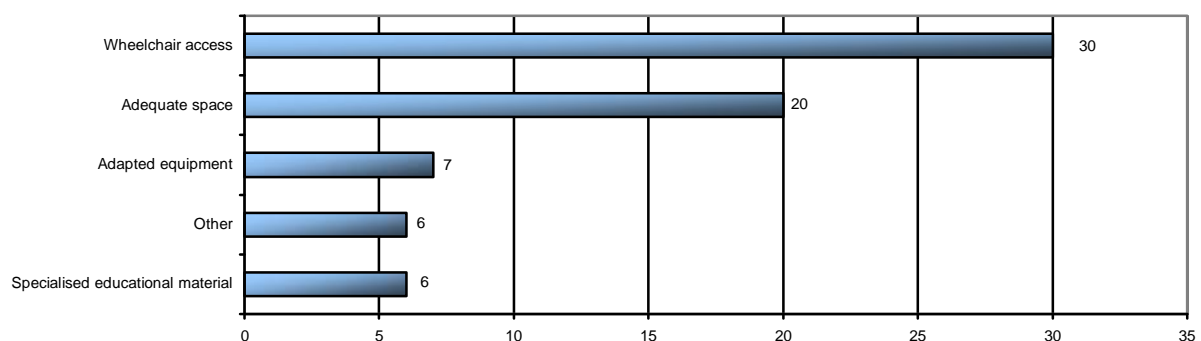
Graph 17: Percentage of respondents with adapted services to provide for children with special needs



On graph 18, it can be observed that among the 22 respondents who stated that they have equipment and a layout that is adapted to provide for children with special needs, 30 of them declared that they have wheelchair access and 20 stated that they have adequate space. Please note that the number of respondents who indicated that they have wheelchair access exceeds the total number of those who responded “yes” to the previous question. This is explained by the fact that some respondents selected this variable even if they responded among the 49% who stated the contrary as indicated in the following graph.

Among the six respondents who specified other types of equipment and/or layouts, some have access to play, observation and/or stimulation rooms.

Graph 18: Number of respondents who have equipment and a layout that is adapted to provide for children with special needs



3.3 Access to resources

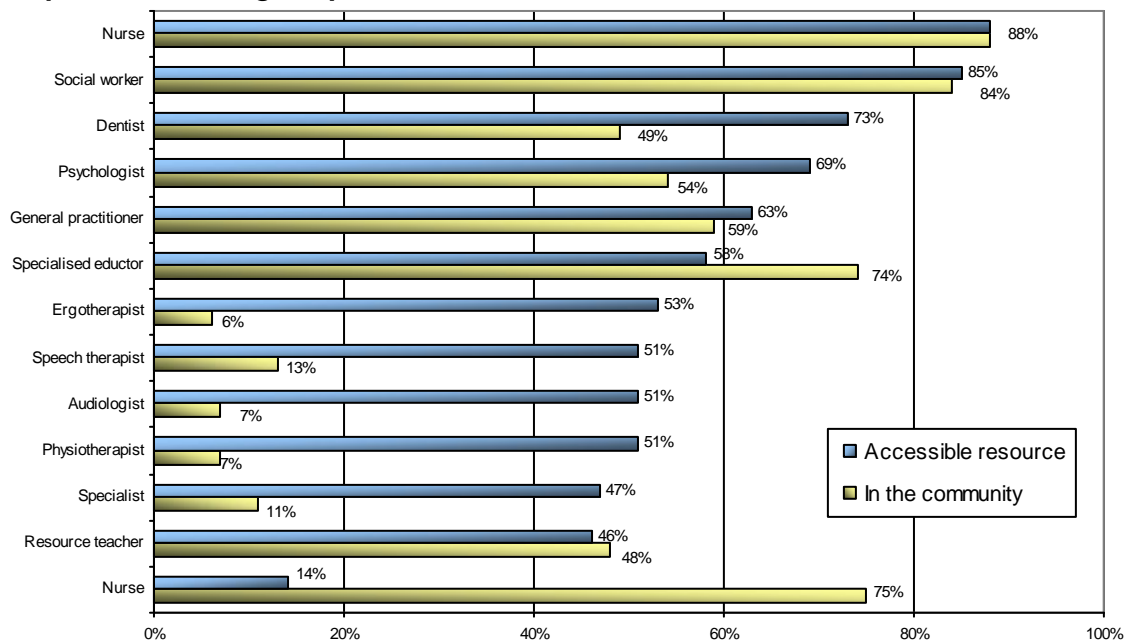
Graph 19 indicates that the two professional resources that are most accessible in the communities are the nurses as well as the social workers. Moreover, ergotherapists, speech therapists, audiologists, physiotherapists as well as specialised physicians represent approximately half of the professional resources that are accessible outside of the community. Moreover, 14% of the respondents indicated that the services of a dietician/nutritionist, dental hygienist and/or sexologist are other professional resources to which their services have access to address the needs of the children.

Table 3: Breakdown of the number of respondents who have access to professional resources

Professional resources	Accessibility			Place	
	Yes	No	No answer	In the community	Outside the community
Nurse	52	3	4	46	5
Dentist	43	5	11	21	22
Specialised educator	34	13	12	25	7
Ergotherapist	31	16	12	2	29
Physiotherapist	30	16	13	2	28
Resource teacher	27	14	18	13	13
Audiologist	30	15	14	2	29
Psychologist	41	9	9	22	18
Speech therapist	30	16	13	4	26
General practitioner	37	10	12	22	18
Specialist	28	16	15	3	24
Social worker	50	4	5	42	5
Other	8	0	51	6	0

For the “place” selection, certain respondents selected both in and outside of the community whereas others did not answer at all.

Graph 19: Percentage of professional resources with accessible services



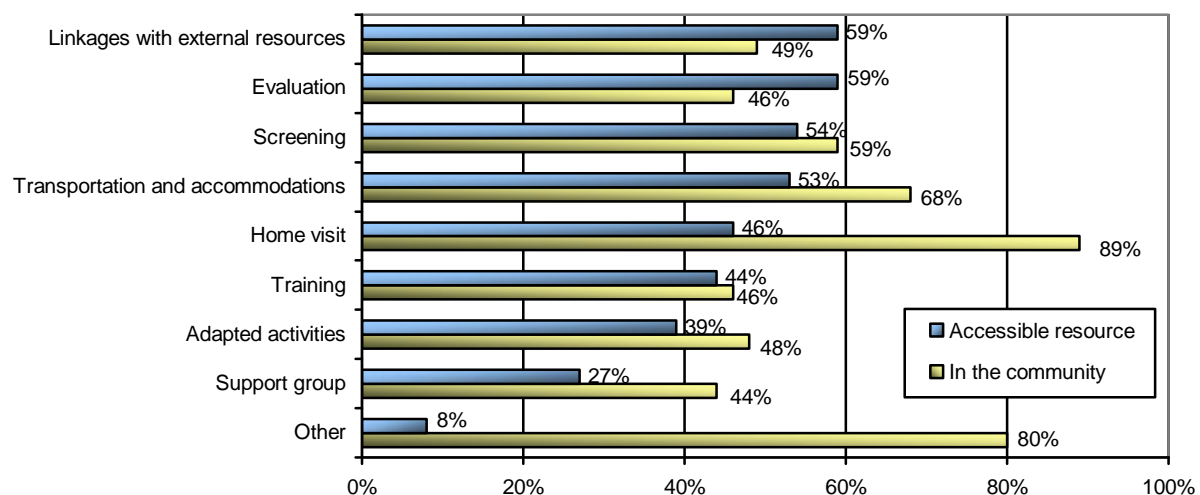
Graph 20 indicates that linkages with external resources, evaluations as well as screenings are the types of services that are the most accessible for children who have special needs and their families. For most, these types of services are accessible within the community. Some (8%) specified other types of services such as parent meetings, stimulation workshops as well as psychosocial follow-up.

Table 4: Breakdown of the number of respondents who have access to the various types of services provided to children who have special needs and their families

Types of services	Accessibility			Place	
	Yes	No	No answer	In the community	Outside the community
Screening	32	12	15	19	10
Evaluation	35	9	15	16	22
Adapted activities	23	15	21	11	15
Linkages with external resources	35	10	14	17	20
Transportation and accommodations	31	11	17	21	13
Training	26	13	20	12	14
Home visits	27	16	16	24	1
Support group	16	20	23	7	9
Other	5	0	54	4	1

For the “place” selection, certain respondents selected both in and outside of the community whereas others did not answer at all.

Graph 20: Percentage of the types of services accessible to children who have special needs and their families



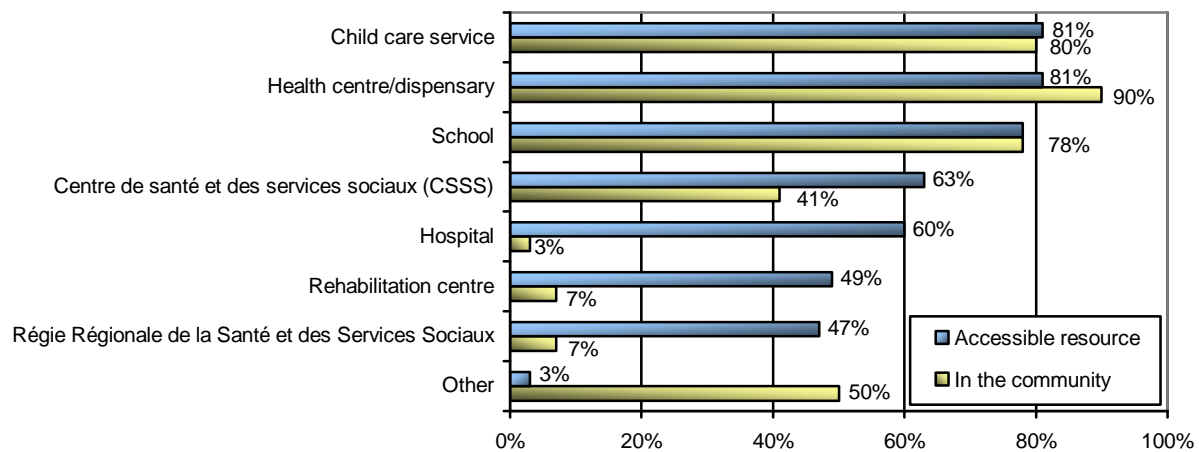
Graph 21 indicates that 81% of the respondents stated that they have access to a child care service or a health centre/clinic to address the needs of children who have special needs. Furthermore, almost all of these types of installations are accessible in the community.

Table 5: Breakdown of the number of respondents who have access to the various types of installations to address the needs of children who have special needs

Type of installations	Accessibility			Place	
	Yes	No	No answer	In the community	Outside the community
Centre de santé et des services sociaux (CSSS)	37	6	16	15	22
Hospital	33	11	15	1	41
Rehabilitation centre	29	12	18	2	36
Régie Régionale de la Santé et des Services Sociaux	28	13	18	2	30
Health centre/dispensary	48	4	7	43	2
School	46	4	9	36	10
Child care service	45	4	10	36	4
Other	2	0	57	1	0

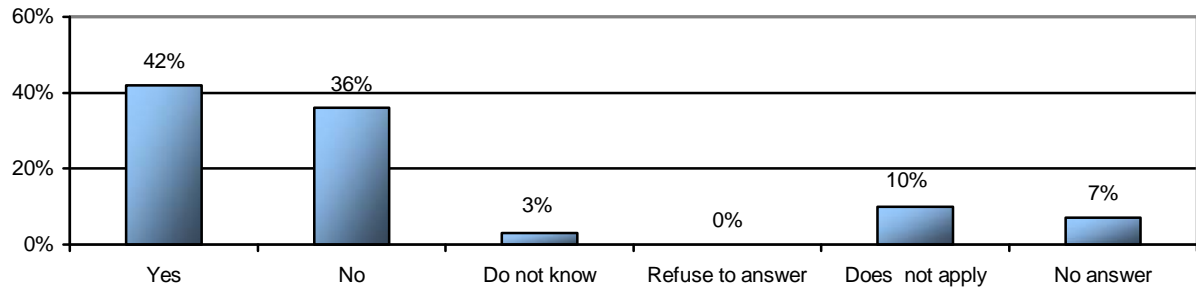
For the “place” selection, certain respondents selected both in and outside of the community whereas others did not answer at all.

Graph 21: Types of installations that the services have access to in order address the needs of children who have special needs (%)



Graph 22 indicates that 42% of the respondents indicated that they are easily able to access services and forms of support that are available to children who have special needs. However, 36% of the respondents indicated the contrary.

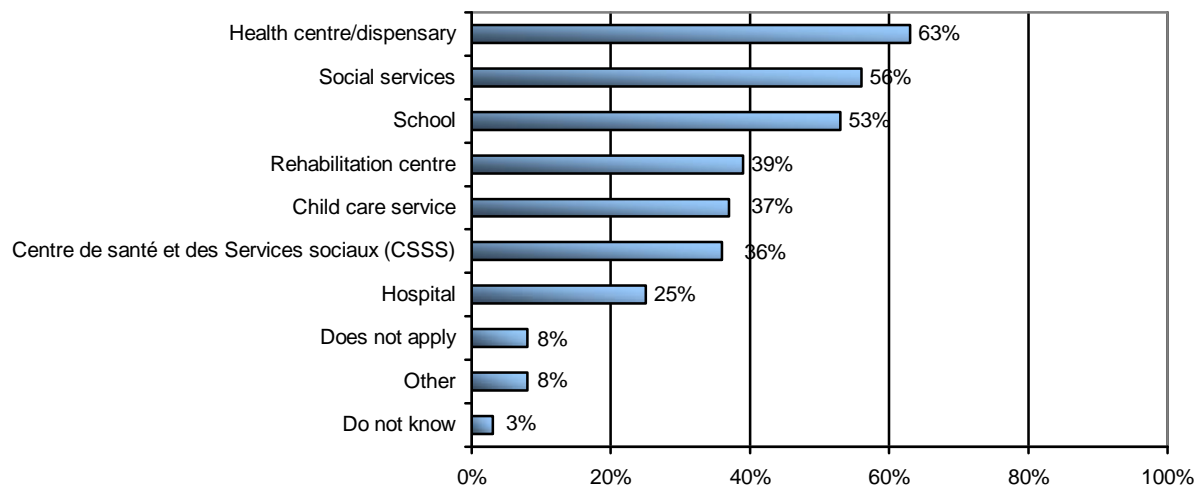
Graph 22: Percentage of respondents who are easily able to access services and forms of support that are available to children who have special needs



The respondents who answered “no” to this question added that the difficulties encountered to access forms of support that are made available to children who have special needs are related to a lack of funding as well as a lack of specialised resources within their service or program. Moreover, other respondents testified that the specialised services that are available outside of the community are difficult to access for those who live in isolated regions, either because the costs related to transportation are expensive and/or the waiting time to meet a specialist is too long.

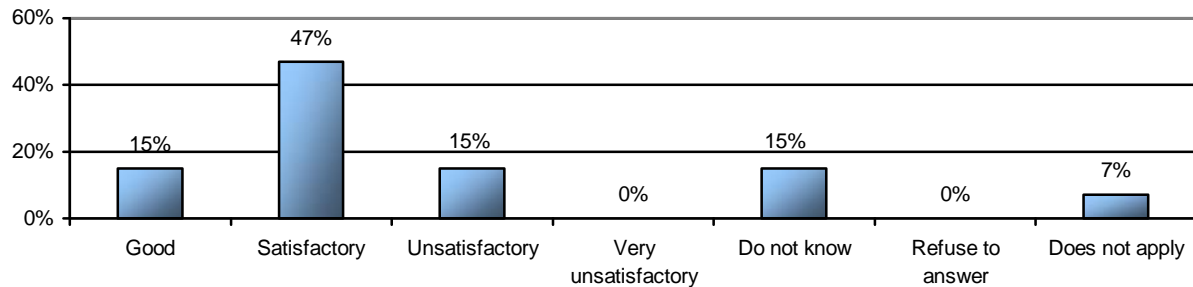
As graph 23 indicates, the health centre/dispensary, the social services or the school are the services that the respondents who answered the questions collaborate with most on a regular basis to ensure the support for a child who has special needs.

Graph 23: Services with which the respondents’ types of services or programs collaborate with to ensure support for a child who has special needs (%)



Graph 24 indicates that 47% of the respondents stated that the level of collaboration between their service or program with external services was satisfactory.

Graph 24: Percentage of the level of satisfaction of the respondents with respect to external services



3.4 Comments

How could the FNQLHSSC support you in the future development of early childhood services?

- ☞ Provide possibilities in terms of professional training for the interveners so that they can acquire specific knowledge on special needs;
- ☞ Have access to accreditation programs so that staff members who work with children who have special needs receive a diploma;
- ☞ Have a specialised resource person in the community to ensure the coordination of services for all children who have special needs;
- ☞ Set of procedures developed on the planning and coordination of the services to be implemented in order to address the needs of the children who have special needs;
- ☞ Dissemination of documentary and educational material that is related to early childhood;
- ☞ Development of specialised tools on special needs;
- ☞ Information on your services and the accessible programs;
- ☞ Additional funding for the implementation of programs;
- ☞ Visits in order to observe our activities and understand our needs;
- ☞ Develop strategies to foster partnerships between the various sectors of a given community;
- ☞ Ensure the connection between the various services and interveners from other communities;
- ☞ Exchange information on the experiences of the other communities;
- ☞ Raise awareness among our politicians (Chiefs and Councillors) on the need to intervene among the First Nations early childhood.

4. Conclusion

On the basis of the results obtained by this portrait, we may state that the early childhood programs and/or services for First Nations children with special needs are limited due to a lack of resources in the communities. We see in particular that:

- ❖ 65.2% of early childhood employees working directly with children who present special needs do not possess any specific training in early child development;
- ❖ 64% of respondents indicated that their program/service does not have a policy for integrating special needs children;
- ❖ 49% of respondents indicated that the equipment and facilities at their centres are not adapted for working with special needs children;
- ❖ Ergotherapists (53%), speech therapists (51%), hearing therapists (51%), physiotherapists (51%) and medical specialists (47%) represent about half of the professional resources accessible outside of the communities;
- ❖ For people living in remote regions, the specialized services available outside their communities are difficult to access because of high transportation costs and/or because of the long waiting list for seeing a specialist.

The reality is such that the inaccessibility of adequate services is preventing special needs children and their families from obtaining the specific services they need. This worrisome situation puts the communities into a difficult position by which they are not able to offer quality and satisfactory services to their members.

The creation of specialized early childhood services for First Nations children with special needs remains a major priority of the FNQLHSSC, which holds the opinion that the implementation of adaptation and integration measures are essential elements for the development of early childhood programs and/or services in the First Nations.

5. RECOMMENDATIONS

To promote conditions that are favourable to the well-being and development of young First Nations children with special needs and in accordance with the Quebec First Nations Health and Social Services Blueprint 2008-2017, the FNQLHSSC recommends the following:

PROMOTE THE DEVELOPMENT OF KNOWLEDGE AND COMPETENCIES IN THE FIRST NATIONS

- ❖ In partnership with educational institutions, implement ongoing training programs allowing First Nations members to:
 - Obtain a specialized early childhood diploma for working with young children who present special needs.
 - Be better equipped to support special needs children and their families.

INNOVATE IN THE DELIVERY OF SERVICES

- ❖ Ensure that young First Nations children with special needs, their families, professionals working directly with them and their communities can benefit from services adapted to the specific characteristics of their respective communities.
- ❖ Support the elaboration of a regional work plan for supporting community workers and First Nations organizations;
- ❖ Support the elaboration of a regional frame of reference for developing specific procedures and standards to promote the integration of special needs children;
- ❖ Implement partnership mechanisms with external specialized resources in the area of early childhood that will meet the needs of the communities (hospitals, groups, associations, etc.);
- ❖ Strengthen the pooling of knowledge and information about early childhood programs and services for special needs children at the local, regional and national levels;
- ❖ Support the creation of a directory of existing resources related to special needs.

QUANTIFY THE REQUIRED CURRENT AND FUTURE INVESTMENTS BY WAY OF RIGOROUS STUDIES

- ❖ In partnership with different specialized resources, participate significantly in the development of research in the area of young First Nations children with special needs, in order to possess clear and rigorous information about the services offered in the communities. This perspective is essential for the effective organization of services at the regional and national levels.

REINFORCE THE EARLY CHILDHOOD FUNDING ALLOCATED TO THE FIRST NATIONS

- ❖ To ensure the implementation and viability of specialized services in the area of special needs, the FNQLHSSC recognizes the critical and indispensable nature of new government investments as well as funding increases proportional to the needs that must be filled with respect to the human, material and technological resources required for taking on the challenge of meeting the needs and expectations of the communities.

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Petite enfance à besoins spéciaux, URL: <http://www.handicaps.ca/petite.enfance/?id=135>

7. ANNEXES

LIST OF GRAPHS

- Graph 1:** *Percentage of the type of service or program represented among the respondents.*
- Graph 2:** *Percentage of respondents represented.*
- Graph 3:** *Percentage of respondents who have children with special needs.*
- Graph 4:** *Characteristics of the listed children who have special needs.*
- Graph 5:** *Percentage of the type of special needs identified within the services or programs.*
- Graph 6:** *Percentage of the type of special needs identified over the past few years within the service or programs.*
- Graph 7:** *Number of employees who work directly with the children.*
- Graph 8:** *Number of positions held by employees who work directly with teachers.*
- Graph 9:** *Number of trainings completed that are specific to early childhood development.*
- Graph 10:** *Percentage of employees who have training that is specific to early childhood development.*
- Graph 11:** *Percentage of respondents who offer early childhood specific professional development activities to the employees in their service or program.*
- Graph 12:** *Percentage of the respondents who are equipped with an integration policy for children who have special needs.*
- Graph 13:** *Percentage of the respondents who possess professional evaluation services to determine if the children have special needs.*
- Graph 14:** *Activities declared by the respondents to determine if the children have special needs (%)*
- Graph 15:** *Percentage of respondents who organise a support plan for children who have special needs.*
- Graph 16:** *Percentage of respondents who coordinate support activities for children who have special needs.*
- Graph 17:** *Percentage of respondents with adapted services to provide for children with special needs*
- Graph 18:** *Number of respondents who have equipment and a layout that is adapted to provide for children with special needs*

- Graph 19:** *Percentage of professional resources with accessible services*
- Graph 20:** *Percentage of the types of services accessible to children who have special needs and their family*
- Graph 21:** *Types of installations that the services have access to in order address the needs of children who have special needs (%)*
- Graph 22:** *Percentage of respondents who are easily able to access services and forms of support that are available to children who have special needs*
- Graph 23:** *Services with which the respondents' types of services or programs collaborate with to ensure support for a child who has special needs (%)*
- Graph 24:** *Percentage of the level of satisfaction of the respondents with respect to external services*

LIST OF TABLES

- Table 1:** *Breakdown of the number of questionnaires filled out by the communities.*
- Table 2:** *Breakdown of the number of questionnaires completed by the early childhood centres in urban areas.*
- Table 3:** *Breakdown of the number of respondents who have access to professional resources*
- Table 4:** *Breakdown of the number of respondents who have access to the various types of services provided to children who have special needs and their families*
- Table 5:** *Breakdown of the number of respondents who have access to the various types of installations to address the needs of children who have special needs*

Wendake, January 23, 2008

GENERAL MAILING

Subject: Regional portrait of special needs among children aged 0 to 6 in the Quebec First Nations

Hello,

The First Nations of Quebec and Labrador Health and Social Services Commission wishes to obtain and study the most recent data concerning special needs in the First Nations communities in Quebec.

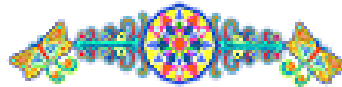
To conduct this study, we are sending a questionnaire to all the First Nations communities in Quebec. After receiving the completed questionnaires, we will analyze the data contained in the answers and will produce a report serving as a reference document for purposes of developing an action plan based on support for the communities. This report will also allow us to formulate recommendations concerning the development of future early childhood services in the area of special needs.

I would ask that you complete and return the attached questionnaire to me no later than February 1, 2008, at the address indicated above. Thank you for giving of your time to play an important part in the development of this project by answering the questionnaire as fully and with as much information as possible.

Sincerely,

Julie Rock
Program Officer – Special Needs
Early Childhood Services Sector

Encl. Questionnaire



QUESTIONNAIRE

INTENDED FOR EARLY CHILDHOOD PROGRAM
(0-6 YEARS) MANAGERS



REGIONAL PORTRAIT OF THE SITUATION
CONCERNING SPECIAL NEEDS
FOR THE FIRST NATIONS OF QUEBEC CLIENTELE
BETWEEN THE AGES OF 0-6 YEARS

DATE: _____

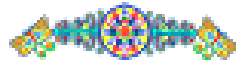
NAME OF COMMUNITY: _____

TYPE OF SERVICE OR PROGRAM: _____

- SOCIAL SERVICES
- SOCIAL DEVELOPMENT—INCOME SECURITY
- HEALTH SERVICES
- EARLY CHILDHOOD CENTRE
- CHILD CARE
- FIRST NATIONS HEAD START PROGRAM
- OTHER, SPECIFY:



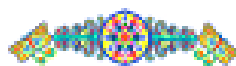
*First Nations of Quebec and Labrador
Health and Social Services Commission*



The term "special needs" refers to the needs of children ages 0-6 years to who we must provide additional resources in order to support their development.

In regards to special needs, the following issues are included:

- ⇒ Exceptional gifts and talents;
- ⇒ Physical, sensory, cognitive or learning problems;
- ⇒ Mental health problems;
- ⇒ Social, cultural, language or family related problems.



Objectives of the current process

In order to define the regional portrait regarding special needs, the Early Childhood sector would like to gather and analyse the most recent data in terms of special needs within the Early Childhood services in the Quebec First Nations communities.

A questionnaire is needed to gather the pertinent data on this issue because of the lack of data. In fact, the current data that was gathered within publications is insufficient to get a portrait of the First Nations children who have special needs.

This data collection will guide us in the drafting of a final report. This report will enable us to develop new strategies within the special needs programs and services in the communities – all the while respecting their culture and their values.

Thus, the final report will serve as a reference document for the development of an action plan that focuses on community support and will permit us to direct our recommendations in a way that fosters the future development of services intended for Early Childhood special needs.

Who can answer the questionnaire?

The questionnaire is intended for those who work with the children ages 0-5 years in the Quebec First Nations communities – excluding the Cree and Inuit. It was developed in such a way as to gather the information relating to the current services that are available to children between the ages of 0-5 years who have special needs. It is divided into the following five (5) sections: clientele description, service description, external resources description, respondent identification and comments.

Those who hold the following positions are likely to answer this questionnaire:

- ❖ Director of a service;
- ❖ Child care coordinator;
- ❖ First Nations Head Start coordinator;
- ❖ Social worker;
- ❖ Early Years Centre coordinator;
- ❖ Teacher;
- ❖ Nurse.

You may answer the questionnaire on your own or as a team. However, if you would prefer to be assisted by someone or if you have any questions, you can communicate in a confidential manner with Ms. Julie Rock, who is in charge of this file at the FNQLHSSC.





Is the questionnaire confidential?

Rest assured that the confidential information that will be included in the questionnaire will remain confidential and will only be used for the purpose of this evaluation. Once the data entry has been performed, all the questionnaires will be destroyed within three (3) years.

This study respects the research protocol that was developed by the Assembly of First Nations of Quebec and Labrador, which implements the principles of ownership, control, access and possession (OCAP).

Will a person in charge of this study contact us?

In order to ensure a proper follow-up, Ms. Rock may contact you in the fifteen (15) days following the forwarding of the questionnaire. If you have already filled out the questionnaire, she will ask you if you have returned it. If you have not yet filled out the questionnaire, she will invite you to fill it out with her during the telephone conversation or at your convenience.

Must I fill out the entire questionnaire and how much time will it take?

It is important to us that you fill out the entire questionnaire. Your answers will enable us to acquire accurate results and therefore obtain a portrait that is as precise as possible. However, your participation is on a voluntary basis. It will take you approximately 30 minutes to fill out the questionnaire.

When must we fill out the questionnaire?

As soon as you receive the questionnaire, it would be important that you fill it out as quickly as possible and return it to us fully completed before February 15, 2008, at noon.

What must I do after having filled out the questionnaire?

Once the questionnaire has been filled out, you can send it to Ms. Julie Rock by fax at (418) 842-7048 or by mail to the following address:

*First Nations of Quebec and Labrador
Health and Social Services Commission
250, Place Chef Michel-Lavoie
Wandake (Québec) G0A 4V0*





1. CLIENTELE DESCRIPTION

For the next two questions, please refer to the glossary annexed at the end of the document.

CLI.1 Currently, does your service include children who have special needs?

- YES (Proceed to question CLI1.1)
- NO (Proceed to question CLI.2)
- DO NOT KNOW
- REFUSE TO ANSWER

CLI.1.1 How many? _____

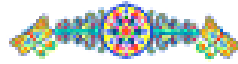
CLI.1.2 Among these, how many:

- Have received a diagnosis _____
- Have not received a diagnosis _____
- Are waiting for an evaluation _____

CLI.1.3 What types of special needs are currently present in your service? (Check all that apply):

- | | |
|--|---|
| <input type="checkbox"/> Allergies | <input type="checkbox"/> Asthma |
| <input type="checkbox"/> Epilepsy | <input type="checkbox"/> Pervasive Developmental Disorder |
| <input type="checkbox"/> Childhood Disintegrative Disorder (CDD) | <input type="checkbox"/> Rett's Disorder (RD) |
| <input type="checkbox"/> Autistic Disorder (or Autism) | <input type="checkbox"/> Asperger's Syndrome (AS) |
| <input type="checkbox"/> Learning Disability | <input type="checkbox"/> Physical disability |
| <input type="checkbox"/> Developmental delay | <input type="checkbox"/> Visual disability |
| <input type="checkbox"/> Hearing Loss | <input type="checkbox"/> Behaviour problems |
| <input type="checkbox"/> Disruptive behaviour disorder | <input type="checkbox"/> Fetal Alcohol Syndrome |
| <input type="checkbox"/> Down Syndrome / Trisomy 21 | <input type="checkbox"/> Attention Deficit Disorder |
| <input type="checkbox"/> Hyperactivity | <input type="checkbox"/> Speech Disorder |
| <input type="checkbox"/> Anxiety or Attachment disorders | <input type="checkbox"/> Tics |
| <input type="checkbox"/> Obesity | <input type="checkbox"/> Other (s), specify:
_____ |
| <input type="checkbox"/> None | _____ |
| <input type="checkbox"/> Do not know | _____ |
| <input type="checkbox"/> Refuse to answer | _____ |

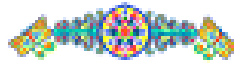




CLJ.2 For the last three years, what types of special needs have been enumerated within your service?

- | | |
|--|---|
| <input type="checkbox"/> Allergies | <input type="checkbox"/> Asthma |
| <input type="checkbox"/> Epilepsy | <input type="checkbox"/> Pervasive Developmental Disorder |
| <input type="checkbox"/> Childhood Disintegrative Disorder (CDD) | <input type="checkbox"/> Rett's Disorder (RD) |
| <input type="checkbox"/> Autistic Disorder (or Autism) | <input type="checkbox"/> Asperger's Syndrome (AS) |
| <input type="checkbox"/> Learning Disability | <input type="checkbox"/> Physical disability |
| <input type="checkbox"/> Developmental delay | <input type="checkbox"/> Visual disability |
| <input type="checkbox"/> Hearing Loss | <input type="checkbox"/> Behaviour problems |
| <input type="checkbox"/> Disruptive behaviour disorder | <input type="checkbox"/> Fetal Alcohol Syndrome |
| <input type="checkbox"/> Down Syndrome / Trisomy 21 | <input type="checkbox"/> Attention Deficit Disorder |
| <input type="checkbox"/> Hyperactivity | <input type="checkbox"/> Speech Disorder |
| <input type="checkbox"/> Anxiety or Attachment disorders | <input type="checkbox"/> Tics |
| <input type="checkbox"/> Obesity | <input type="checkbox"/> Other (s), specify: |
| <input type="checkbox"/> None | _____ |
| <input type="checkbox"/> Do not know | _____ |
| <input type="checkbox"/> Refuse to answer | _____ |





2. SERVICE DESCRIPTION

2.1 Human Resources

SER.2.1.1 Currently, how many employees in your service work directly
- with children between the ages of 0-6 years? ____
- with special needs children? ____

SER.2.1.2 Among these, indicate the number of employees who occupy the following positions:

Child care assistant educator	_____
Child care educator	_____
Special education teacher	_____
Social worker	_____
Psycho-educator	_____
Teacher	_____
Teacher's aide	_____
Nurse	_____
Others, specify	_____

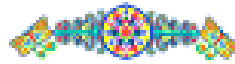
- DO NOT KNOW
- REFUSE TO ANSWER
- NOT APPLICABLE

SER.2.1.3 What specific training sessions that are specific to Early Childhood development have been completed by the previously enumerated employees?

- _____
- _____
- _____
- _____
- _____
- _____
- _____

- DO NOT KNOW
- REFUSE TO ANSWER
- NOT APPLICABLE





SER2.1.4 Do you provide Early Childhood specific professional development to the employees in your service who work with the children?

YES, specify:

- NO
- DO NOT KNOW
- REFUSE TO ANSWER
- NOT APPLICABLE

2.2. Tools

SER2.2.1 Does your service have an integration policy for children who have special needs?

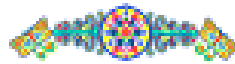
- YES
- NO
- DO NOT KNOW
- REFUSE TO ANSWER

SER2.2.2 Are the children in your service the object of a professional evaluation to determine if they have special needs?

- YES
- NO
- DO NOT KNOW
- REFUSE TO ANSWER
- NOT APPLICABLE

If so, in what manner is the process used?





SER2.2.3 Is your service capable of organising a support plan for a child who has special needs?

- YES
- NO
- DO NOT KNOW
- REFUSE TO ANSWER
- NOT APPLICABLE

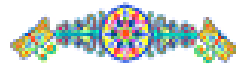
SER2.2.4 Is your service able to coordinate support activities for a child who has special needs?

- YES
- NO
- DO NOT KNOW
- REFUSE TO ANSWER
- NOT APPLICABLE

SER2.2.5 Enumerate the screening and/or evaluation tools that are used by your service for children who have special needs:

- _____
- _____
- _____
- _____
- _____





2.3. Equipment and lay-out

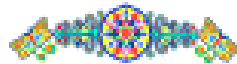
SER2.3.1 Is your service adapted to cater to children who have special needs?

YES, does it have (check all that applies):

- Adapted equipment
- Special didactical material
- Wheelchair access
- Adequate space
- Others:

- NO
- DO NOT KNOW
- REFUSE TO ANSWER



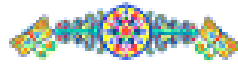


3. ACCESSIBILITY TO RESOURCES

RES3.1 What are the external professional resources to which your service has access in order to provide for the needs of these children?

PROFESSIONAL RESOURCES	ACCESSIBILITY		PLACE	
	YES	NO	IN THE COMMUNITY	OUTSIDE THE COMMUNITY
Nurse				
Dentist				
Special Education teacher				
Occupational therapist				
Physiotherapist				
Resource teacher				
Audiologist				
Psychologist				
Speech therapist				
General practitioner				
Specialist				
Social worker				
Other, specify:				
Other, specify:				

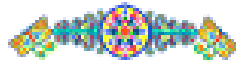




RES3.2 What are the types of services that are offered to children with special needs and for their families?

TYPES OF SERVICES	ACCESSIBILITY		PLACE	
	YES	NO	IN THE COMMUNITY	OUTSIDE THE COMMUNITY
Screening				
Evaluation				
Adapted activity				
Uaison with external resources				
Transportation and accommodations				
Training				
Home visit				
Support Group				
Social worker				
Other, specify: _____				
Other, specify: _____				





RES3.3 What types of installations does your service have access to in order to address the children's needs?

TYPE OF INSTALLATION	ACCESSIBILITY		PLACE	
	YES	NO	IN THE COMMUNITY	OUTSIDE THE COMMUNITY
Centre de santé et des services sociaux (CSSS)				
Hospital				
Rehabilitation centre				
Régie régionale de la Santé et des Services Sociaux				
Health centre/Dispensary				
School				
Child Care				
Other, specify: _____				
Other, specify: _____				

RES3.4 Are you easily able to access services and support methods that are available for children with special needs? (Screening, evaluation, follow-up with specialists, etc.)

YES

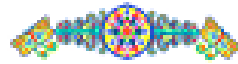
NO, explain:

DO NOT KNOW

REFUSE TO ANSWER

NOT APPLICABLE





RES3.5 With which external services do you collaborate in order to ensure the support of a child who has special needs?

- Health centre/dispensary
- Centre de Santé et des Services Sociaux (CSSS)
- Hospital
- Rehabilitation centre
- Régie Régionale de la Santé et des Services Sociaux
- Social services
- School
- Child care
- Others, specify:

- Do not know
- Refuse to answer
- Not applicable

RES3.6 How would you describe the level of cooperation between your service and external services? (Health centre, CLSC, hospital, etc.)

- Very satisfactory
- Satisfactory
- Unsatisfactory
- Very unsatisfactory
- Do not know
- Refuse to answer
- Not applicable





GLOSSARY

This section is not a comprehensive list of disabilities. It is intended to be used as a reference for questions relating to this evaluation.

Allergies: An allergy is an abnormal reaction by the organic system to a given substance – referred to as an allergen.

Asthma: Asthma is a lung disease that affects breathing.

Epilepsy: Epilepsy is a chronic neurological disorder that is characterized by recurrent seizures that are due to an abnormal neuronal activity in the brain.

Pervasive Developmental Disorder, Not Otherwise Specified: A severe and invasive alteration of reciprocal social interaction or of verbal and non-verbal communication skills – such as stereotypical behaviours, interests and activities.

Childhood Disintegrative Disorder (CDD): This disorder is characterized by a severe regression in several areas after an apparently normal period of development of at least two years, particularly in regards to skills in the areas of communication, social, play and adaptive behaviour in relation with their age.

Rett's Disorder (RD): Rett's disorder is characterized by the appearance of certain deficiencies after a period of normal development.

- (1) deceleration of the rate of head growth between 5 to 48 months;
- (2) between 5 and 30 months, loss of previously acquired intentional manual skills, followed by the appearance of stereotypical hand movements (i.e.: wringing or washing hands);
- (3) problems with socialisation in the early stages of the disease (even though certain forms of social interaction can eventually develop);
- (4) Appearance of coordination difficulties in regards to trunk movement or when walking;
- (5) severe alteration of expressive and receptive language development, associated with a severe psychomotor delay.

Typically, Rett's syndrome is associated with a severe mental retardation. Epileptic seizures are often present.

Autism spectrum disorder (or autism): Autism is a developmental condition characterized by the three (3) following elements: severe deficiency in the establishment of relationships, lack of verbal and non-verbal communication skills, pattern of specific behaviours (fascination for an object or certain parts of objects, attachment to routine and restrained interests, resistance to change and vivid worry).

Asperger Disorder (AD): This deficiency is characterized by a severe and prolonged alteration of social interaction and the development of methods of behaviour, activity and interest that are restrained, repetitive and stereotypical. There is no delay in language skills, or a significant loss of developmental skills.





Learning Disability: This expression refers to several disabilities that can affect the acquisition, organization, retention, comprehension or processing of verbal or non-verbal information.

Visual disability: Those who experience a visual disability present, both from a visual acuity as well as a field of vision perspective, significant and persistent disabilities that are susceptible to retrain their social participation.

Hearing loss: Hearing impairment is defined as being a decrease in sonar detection, which ranges from a simple decrease in hearing acuity to a complete loss of sound, voice and noise detection.

Behaviour problems: The whole of the behaviours, both repetitive and persistent, in which the fundamental rights of others or the standards and social rules corresponding to the age of the subject are confused or baffled.

Disruptive Behaviour Disorder: A deficiency that is characterized by oppositional or confrontational actions or behaviours.

Foetal Alcohol Syndrome: Foetal Alcohol Syndrome is a range of physical and behavioural anomalies that appear in children who were exposed to alcohol during their mother's pregnancy.

Down Syndrome/Trisomy 21: Down syndrome or Trisomy 21 is characterized by an intellectual deficiency as well as by a particular physical appearance.

Attention Deficit: Attention deficit is an excessive tendency to be distracted. Children who have an attention deficit experience difficulty in concentrating, paying attention, focussing on work or completing certain tasks without being distracted by their environment. There are three different types of attention deficit: attention deficit with hyperactivity, attention deficit without hyperactivity and hyperactivity without attention deficit.

Hyperactivity: Hyperactivity is apparent in the physical behaviour of a child. A child who is hyperactive moves all the time and presents impulsive issues when facing various situations.

Speech disorder: Speech disorder is defined by a delay in regards to a normal rate of language development with the presence of abnormalities in the development.

Anxiety or attachment disorders: Excessive or inappropriate anxiety at the stage of development concerning separation with the home or the people to who the subject is attached.

Tics: Presence of multiple motor tics and of one or many vocal tics, at any time during the evolution of the disease but not necessarily in a simultaneous fashion. (A tic is a movement, or vocalization, that is sudden, rapid, recurring, non rhythmic and stereotypical.)

Sources:

- American Psychiatric association, DSM-IV, Manuel diagnostique et statistique des troubles mentaux. Traduction française, Paris, Masson, 1995, 1056p.
- Learning Disabilities Association of Quebec: <http://www.aqeta.qc.ca>





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