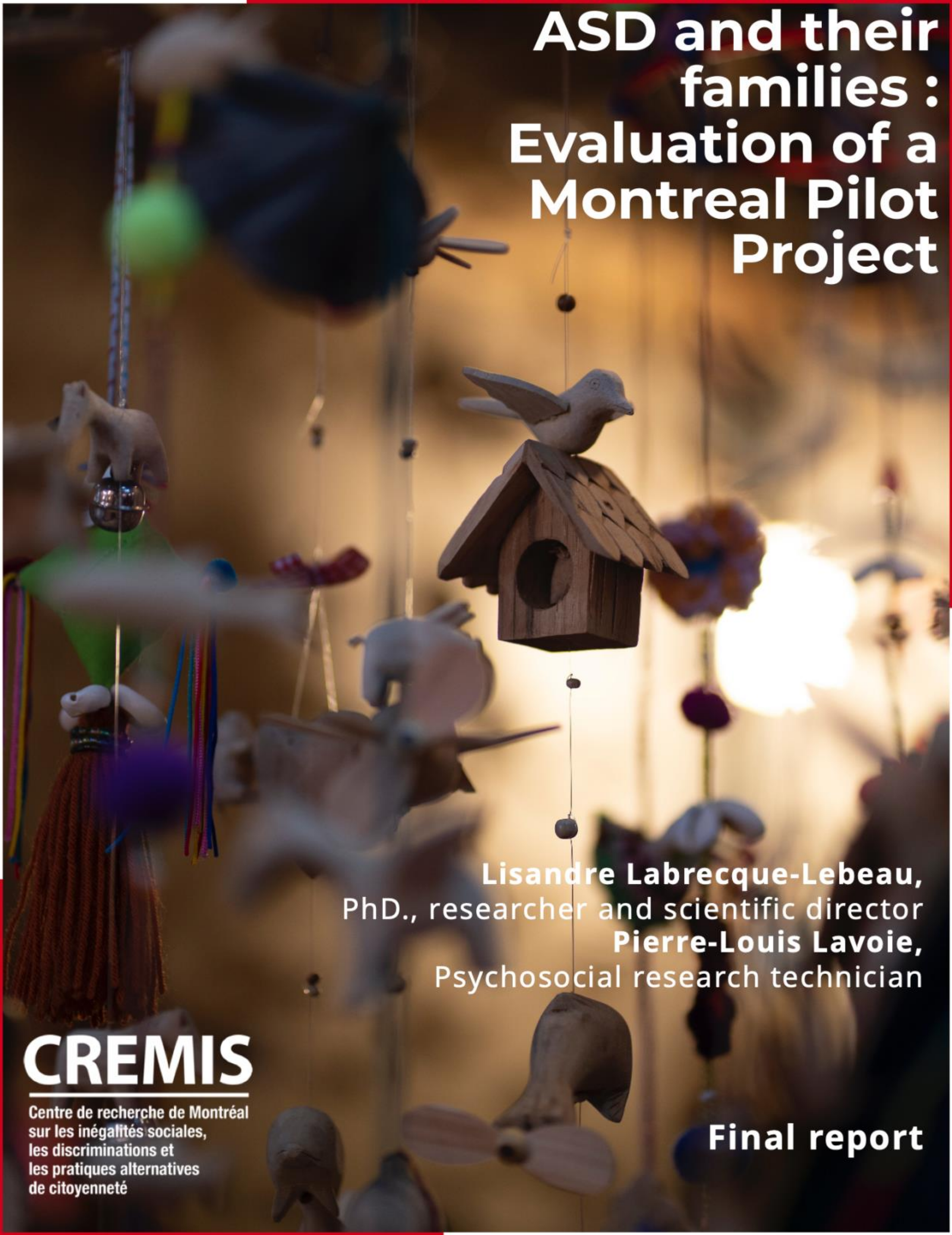

Patient navigation with children with ASD and their families : Evaluation of a Montreal Pilot Project

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LIST OF ACRONYMS

ABA: Applied behaviour analysis

ASD: Autism spectrum disorder

CIUSSS: Centre intégré universitaire de santé et de services sociaux (Integrated University Health and Social Services Centre)

CLSC: Centre local de services communautaires (Local Community Service Centre)

GDD: Global developmental delay

ID: Intellectual disability

IP: Intervention plan

ISP: Individualized service plan

MSSS: Ministère de la Santé et des Services sociaux (Ministry of Health and Social Services)

PN: Patient navigator

RSSS: Réseau de la santé et des services sociaux (Health and Social Services Network)

Background and issues

In an effort to find solutions that better meet the needs of children diagnosed with global development delay (GDD), intellectual disability (ID) or autism spectrum disorder (ASD), along with their families, the Miriam Foundation, the Institut national d'excellence en santé et services sociaux (INESSS) and Quebec's Ministry of Health and Social Services (MSSS) reached an agreement with the five CIUSSS in the Montreal area to provide funding for hiring six patient navigators (PN). The working group responsible for this pilot project then added a research team to document the experience and improve their understanding of patient navigation for cases of ID, ASD, and GDD.

TABLE 1: FOCUS AND DELIVERABLES OF ORIGINAL PROPOSAL

General objective: Improve our understanding of the practice of patient navigation for cases of ID, ASD and GDD, and identify the types of patient navigation most likely to meet the needs of targeted children and their families.

Theme 1: Modelling patient navigation

1. Document the work of PNs in the Montreal pilot project:
    a) Interviews with families
    b) Observation and interviews with PNs: Describe their practice and main tasks.
2. Identify a typology for practicing patient navigation:
    a) Interviews with families: How does their PN work for them?
    b) Observation and interviews with PNs
3. Document the needs and expectation of families regarding their PN's support and the perceived impact of the support received:
    a) Interviews with families: Expectations of the PN's role and their ability to fulfill it; perceptions of the impact
    b) Observation and interviews with PNs: What do they aim to achieve through their work, with regard to their representations of the needs of children and families?

Theme 2: Analyzing the impact of patient navigation

4. Document the factors that influence the various types of patient navigation in participating organizations:
    a) Interviews with families: What are the reasons for and against providing PN support?

    b) Observation and interviews with PNs: What factors influence their interventions? Review of the issues observed with the practice.

5. Measure the ability of different types of patient navigation to satisfy the families served and meet their needs:

    a) Results of family interviews
    b) Telephone questionnaire to the families: Based on the results of objectives 2 and 3

6. Compare the satisfaction of families, the responsiveness to their needs and the timeliness of access to services based on whether or not a patient navigator is assigned to a child's case.

    a) Results of interviews with the families
    b) Telephone questionnaire to the families: Based on results of objectives 2 and 3
    c) Administrative data (delays in accessing services with and without a PN)

Theme 3: Developing an emerging model of patient navigation

7. Draw up a comparative table of the different types of patient navigation, describing their ability to meet the needs of families and the contextual factors that support their implementation:

    a) Observation and interviews with PNs
    b) Analysis of objectives 2 and 4

8. Identify obstacles and factors conducive to certain tasks associated with the work of a patient navigator and perceived as essential to meeting the needs of families:

    a) Analysis of objectives 2 and 4

9. Develop an "ideal" model of patient navigation given the contextual realities of Montreal CIUSSS, in relation to recognized patient navigation practices.

Patient navigation is a practice that was formalized in New York's Harlem neighbourhood in the 1990s, more specifically in oncology units (Cantril & Haylock, 2013). This type of intervention originated in an intention to address the social inequalities of an often labyrinthine health-care system that did not offer the same opportunities to all. Underinsured, disadvantaged and racialized populations were the groups that faced the greatest obstacles to accessing quality cancer care at that time (Cantril & Haylock, 2013). The practice of navigation then expanded to other professions (e.g. nursing) and statuses (sometimes patient volunteers), as well as other areas of habilitative and rehabilitative care and services, including intellectual disability, autism spectrum disorder and global developmental delay, such as what we are interested in here.

To obtain services in Quebec's health and social services network, children with an ID, ASD or GDD, along with their families, are faced with long waiting lists (sometimes numbering in years), must knock on many doors (e.g., pediatrician, psychologist, CIUSSS, CRDIQ), contact different ministries (e.g. Health, Education, Transportation, Family) and coordinate the various services to which they have access, if necessary. Therefore, patient navigation becomes a promising practice to facilitate not only the steps taken by families, but also their access to and coordination of care and services.

The Health and Social Services Network, for its part, seems to agree and refer to the same thing when it comes to patient navigation, but no one knows exactly what it is. Those involved know that it seems to work, but do not know precisely how patient navigators were trained or learned the job. They all seem to embrace the concept of "navigation" as the focal point of their actions, but the tasks they favour seem to vary according to context (e.g., program requirements and characteristics), their training (mainly psychoeducation or social work) and their clients (neighbourhood, socioeconomic status, migration status, etc.).

Based on interviews with families and patient navigators, observations of the practice, as well as an analysis of administrative data and data from a survey of parents concerned, we were able to identify the concrete practices that constitute patient navigation for ID-ASD-GDD as part of the pilot project conducted at five Montreal CIUSSS locations. When taking into account the needs and expectations of families, we then verified whether these practices were satisfactory and suited to their realities, in order to construct an ideal model of patient navigation.

Description of the data and methodology

This research project and its evaluation involved two categories of stakeholders: parents of children with ID-ASD-GDD and the navigators involved in the pilot project. We collected data from four types of evaluations: semi-structured interviews with various stakeholders, on-site observations of the work of PNs, a telephone survey of families, as well as the compilation and analysis of administrative data provided by the five major CIUSSS on the Island of Montreal.

Who are the PNs?

The research involved six caseloads across five CIUSSS (two for the CIUSSS de l'Est-de-l'Île-de-Montréal).

- Eleven PNs were closely or remotely involved in the research.[1]
- Six PNs were working in their positions at the time of the interviews.
- Two former PNs were interviewed and shared their thoughts on this practice after the fact.
- Of the 11 PNs, seven were trained in social work and four in psychoeducation.

TABLE 2: QUALITATIVE DATA COLLECTED BY CASELOAD

Case load	PN - alias	Training	Interviews	Observation blocks	No. of families interviewed
1	Alexandra	SW*	2/2	6/6	2/2
2	Rachel	SW	2/2	6/6	0/2
	Mylène	SW	--	--	2/2
3	Karine	PsEd	1/2	4/6	0/2
	Rebecca	SW	--	--	0/2
4	Marilou	PsEd	2/2	6/6	2/2
	Estelle	SW	--	--	--
5	(Claude)	(SW)	(1)	--	--
	Adrienne	SW	2/2	6/6	2/2
6	(Suzanne)	(PsEd)	(1)	--	--
	Zoé	PsEd	2/2	6/6	2/2

* SW = social work, PsEd = psychoeducation

(In parentheses) = former PNs at the time of the interview

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[1] Due to staff turnover and the duration of the research project, interviews with the PNs were not always aligned with observations and interviews with families. For example, for a given CIUSSS, the families interviewed may be part of a PN's caseload but the interview was conducted by the PN's predecessor.

Patient navigation suffers from confusion caused by various factors. Firstly, although the six practitioners in the pilot project officially have the title of “navigator,” a number of practitioners from the Health and Social Services Network also have this title (e.g., “educator/navigator”).

In addition, it is important to **contextualize the data with the fact that families generally do not know which PN is assigned to their case.** Parents generally distinguish the various practitioners involved in their case by their first names, and to a lesser extent, by their title (e.g. “my social worker”). Although we attempted as much as possible to identify moments when families talked about their PNs during our conversations, it is not always clear in the interviews and survey that they are talking specifically about their assigned PN for the pilot project.

However, by the nature of our questions and conceptualizations, which concern the types of actions taken as part of patient navigation, **it can be argued that this research still measures and evaluates “navigation tasks” used within various clinical practices.**

Who are the families?

- Eleven families served by the five CIUSSS were interviewed, with the exception of one caseload for which no family could be recruited.
- There were eight children with ASD and one child with an ID. This data is consistent with administrative data provided by the CIUSSS.
- Seven families out of 11 are recent immigrants (5-10 years).

TABLE 3: CHARACTERISTICS OF PARTICIPATING FAMILIES (INTERVIEWS)

Interview	Participant	Child’s diagnosis	Immigration status
1	Mother	ASD	Unspecified
2	Father	ASD	Yes
3	Mother	ASD	Yes
4	Mother	ASD	Yes
5	Mother	ID (Down syndrome)	Unspecified
6	Mother	ASD	Yes
7	Mother	Other – ASD services	Unspecified
8	Father	ASD	Yes
9	Grandmother	ASD	Unspecified
10	Mother	ASD	Yes
11	Mother	ASD	Yes

Most of the families involved in the study are recent immigrants (5-15 years); this data is also confirmed in the survey. It is risky to speculate on the reasons for this high representation. However, several participants interviewed raised the hypothesis that immigrant families attempting to integrate may make greater demands on the public system or access the services they need less quickly, thereby remaining at a stage requiring navigation. However, the same participants also pointed out that due to the way services are organized, all families (whether or not they are immigrants or receive private services) are supposed to go through the same process when requesting services, therefore can theoretically be tracked in the system.[2]

Most of children with ASD (82%) benefitted from a patient navigator during the pilot project. Several hypotheses can be explored as to why. Families with a child who has an ID or GDD may have different needs or access other services. In addition, it is important to note that in the information gathered, there is only very rarely any mention of global developmental delay, since this category is believed to be more of a diagnostic hypothesis seeking clarification in the child's development.

Semi-structured interviews

- Eleven interviews were conducted with 11 families; ten were recorded.
- Eleven PNs were interviewed; five PNs were interviewed twice regarding the observation blocks.

Observations

- Six observation blocks were conducted per caseload, except for one PN, who participated in four out of six blocks before leaving the job.
- Observations took place mostly at a CLSC or at the family's home.

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[2] These are the explanations put forward by the people we met, and therefore their interpretations of the situation. More data and analysis are required to better define the problem.

TABLE 4: NUMBER OF OBSERVATION SESSIONS CONDUCTED BY LOCATION AND TYPE OF STAKEHOLDER PRESENT

Location	No. of observation blocks	Percentage
Legal aid	1	3%
CLSC	13	38%
Home	11	32%
Rehabilitation centre	4	12%
CPE - daycare	2	6%
School	1	3%
Hospital	1	3%
Community organization for ID-ASD	1	3%

Stakeholders present	Num. of observation blocks	Percentage
Parents	24	71%
CIUSSS representatives	11	32%
Child	8	24%
School representatives	3	9%
Siblings	2	6%
Representatives from daycare environment	2	6%
Community or partner representatives	2	6%
PN only	1	3%

All information gathered (verbatim interviews and observation notes) underwent qualitative analysis using an emergent approach (Paillé and Muchielli, 2012). After skimming the material and in light of the research questions, a coding tree was created. The material was then coded using NVivo software based on the categories created.

Administrative data from the five CIUSSS

The data that the CIUSSS were able to provide are fragmentary and inconsistent. Therefore, they must be put into context and interpreted with caution. What's more, in the case of access times, which could not be adequately measured using administrative data, we partially got around this parameter by including certain questions in the survey to compensate for the lack of data in this area.

Targeted variables requested from the CIUSSS

- User's telephone number (parent or legal guardian)
- User's file number
- Name of the patient navigator on file (if applicable)
- Types of services (programs or services such as IBI, habilitation/rehabilitation, residential integration, etc.)
- Date of access to these services (start date of program/service)
- Child's age
- Diagnosis (ID, ASD, ID and ASD, PDD,[3] GDD, etc.)
- Degree of prioritization of the request for access to services
- Total number of services since the user's first request for service
- Total number of cases in the caseload of the patient navigator on file
- User's postal code

Targeted cases

- Targeted families: All children aged 0-7 who have a GDD, ID or ASD that is part of the caseload of the patient navigator involved in the pilot project
- Control families: Ten children aged 0-7 with a GDD, ID or ASD who are not followed by a patient navigator involved in the pilot project (randomly selected)

Data collection

- Data was collected over a period of five months.
- The initial request for administrative data was sent to the five participating CIUSSS on February 20, 2019, and the final requested data were received on July 8, 2019.
- Due to the inability of the CIUSSS to provide us with certain data, we were only able to conduct a partial analysis, particularly regarding delays in access to services. Some questions concerning this aspect were added to the survey to compensate for the lack of data.

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[3] The diagnosis of pervasive developmental disorder is sometimes found in the CIUSSS data, despite the disappearance of this diagnostic category.

TABLE 5: SUMMARY OF ADMINISTRATIVE DATA COLLECTED

Variables	CCOMTL	CCSMTL	CEMTL	CNIM	COMTL
File number	🟩	🟩	🟩	🟩	🟥
Telephone number	🟩	🟩	🟩	🟩	🟥
Postal code	🟩	🟩	🟩	🟩	🟥
Name of PN on file (control group)	🟩	🟩	🟩	🟥	🟨
Type of program/service	🟥	🟩	🟥	🟨	🟩
Date of access to service	🟨	🟥	🟥	🟨	🟨
Child's age	🟩	🟩	🟩	🟩	🟩
Child's diagnosis	🟩	🟩	🟨	🟩	🟩
Degree of prioritization of request	🟨	🟩	🟨	🟨	🟨
Calculated field: Total no. of services since first request	🟥	🟩	🟥	🟨	🟩
Calculated field: Total no. of cases in PN's caseload	53	38	64	38	48

→ **Table 5** presents a summary of the administrative data obtained from the various CIUSSS. Missing data are shown in red, partial data in yellow.[4]

→ We noted that there is more missing or partial data related to the various services requested and/or received by users.

→ Only one valid database of user profiles could be created, due to the missing data related to the services.

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[4] The research team can provide a history of the process and details of the data collected and missing, if needed.

TABLE 6: USER PROFILES (ADMINISTRATIVE DATA)

User profiles (administrative data)		Pilot project		Control group	
		n	%	n	%
Patient navigator	**CCOMTL**	**53**	**19%**	10	**20%**
	Navigator #1	53	19%	-	-
	CCSMTL	**38**	**14%**	10	**20%**
	Navigator #1	38	14%	-	-
	CEMTL	**101**	**36%**	10	**20%**
	Navigator #1	47	17%	-	-
	Navigator #2	17	6%	-	-
	Navigator #3	37	13%	-	-
	CNIM	**38**	**14%**	10	**20%**
	Navigator #1	38	14%	-	-
	COMTL	**48**	**17%**	10	**20%**
	Navigator #1	48	17%	-	-
Total		**278**	**100%**	**50**	**100%**
Diagnosis	ASD	224	81%	36	90%
	ID	47	17%	3	8%
	Down syndrome	3	1%	-	-
	ID and ASD	2	1%	1	3%
	Physical disability	1	0%	-	-
Total		**277**	**100%**	**40**	**100%**
Age (1-10)[5]		n	Avg.	n	Avg.
	CCOMTL	53	4.5	10	4
	CCSMTL	38	5.1	10	4.3
	CEMTL	101	4.8	10	5.3
	CNIM	38	5.1	10	4.6
	COMTL	48	5.8	10	5.2
Total/average		**278**	**5.0**	**50**	**4.7**

→ As shown in **Table 6**, a total of 328 families were targeted (pilot project: 278; control group: 50).

→ More than a third of the users came from the *CEMTL* (pilot project: 30%).

→ Most users were diagnosed exclusively with ASD (pilot project: 81%; control group: 90%) or ID (pilot project: 17%; control group: 8%).

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[5] Given the relatively small number of targeted users, data concerning those over seven years of age (n=7 users) were included in the overall data, in order to obtain a larger pool of potential respondents to the survey. We believe this had a minimal impact on the representativeness of the sample.

Telephone survey

The telephone survey was conducted by a specialized firm from December 8 to 21, 2020. Of the total population under study (328 families), 290 agreed to be interviewed (directly or indirectly[6]) and 122 interviews were conducted. The response rate was 37.2%, resulting in a **maximum margin of error** for the target population of **± 7.03%,** 19 times out of 20 (**Table 7**).

TABLE 7: SUMMARY OF TELEPHONE CALLS (SURVEY; SOURCE: LÉGER)

Basic sample	328
Consented to interview	290
Unable to contact	21
No service	19
Non-residential	2
Not included in survey	25
Foreign language	9
Ineligible	1
Unqualified	6
Wrong number	9
Effective sample	244
Incomplete interviews	122
Refused	44
No answer	9
Voicemail	56
Incomplete	5
Made an appointment	8
Complete interviews	122

The table on the next page (**Table 8**) summarizes the profiles of survey respondents.

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[6] Indirect interviews: Families were sent a letter and given the option of declining to be contacted by an external polling firm. Direct interviews: Families were contacted by their PN to find out whether they were willing to be contacted for the survey.

Table 8: Profile of respondents (parent or legal guardian)

Profile of respondents (parent or legal guardian)		Pilot project		Control group	
		n	%	n	%
Gender	Male	22	22%	4	17%
	Female	77	78%	19	83%
Total		**99**	**100%**	**23**	**100%**
Age group	Less than 25 years old	1	1%	1	4%
	25 to 29 years old	4	4%	-	-
	30 to 34 years old	19	19%	3	13%
	35 to 39 years old	19	19%	4	17%
	40 to 44 years old	34	34%	10	44%
	45 years or older	22	22%	5	22%
Total		**99**	**100%**	**23**	**100%**
Number of children at home	1 child	24	24%	6	26%
	2 children	43	43%	7	30%
	3 children	22	22%	7	30%
	4 children	7	7%	2	9%
	5 children	2	2%	-	-
	6 children	1	1%	1	4%
Total		**99**	**100%**	**23**	**100%**
Gross annual family income	Less than $30,000	23	25%	7	33%
	$30,000 to $39,999	12	13%	4	19%
	$40,000 to $49,999	1	12%	1	5%
	$50,000 to $59,999	9	10%	-	-
	$60,000 to $69,999	9	10%	-	-
	$70,000 to $79,999	3	3%	4	19%
	$80,000 to $99,999	8	9%	1	5%
	$100,000 or more	19	20%	4	19%
Total		**94**	**100%**	**21**	**100%**
Born in Canada	Yes	25	25%	4	17%
	No	74	75%	19	83%
Total		**99**	**100%**	**23**	**100%**
Number of years in Canada (born outside Canada)	Less than 5 years	3	4%	2	11%
	5 to 9 years	22	30%	4	21%
	10 to 14 years	24	33%	7	37%
	15 to 19 years	10	14%	4	21%
	20 years or more	14	19%	2	11%
Total		**73**	**100%**	**19**	**100%**
Marital status	Single	9	9%	1	4%
	Married or common-law	76	78%	19	83%
	In a relationship (with no marital status)	2	2%	1	4%
	Separated or divorced	11	11%	2	9%
Total		**98**	**100%**	**23**	**100%**
Education	Elementary school (7 years or less)	3	3%	-	-
	High school (general or vocational training - 8 to 12 years)	19	20%	7	30%
	CEGEP (pre-university training, technical training, certificates, attestations or diplomas)	16	16%	4	17%
	University (traditional courses, certificates, diplomas, undergraduate, masters or doctorate)	59	61%	12	52%
Total		**97**	**100%**	**23**	**100%**
Respondent group	CCSMTL	13	11%	-	-
	CNIM	12	10%	-	-
	CCOMTL	14	12%	-	-
	CEMTL (LT and SLSM)	26	21%	-	-
	CEMTL (PDI)	17	14%	-	-
	COMTL	17	14%	-	-
	Control group	-	-	23	19%
Total	Total	99	100%	23	100%

→ The control group made up 19% of the sample (23 respondents out of a total of 122) compared to all the other CIUSSS, allowing us to make certain statistical comparisons between pilot project respondents and the CIUSSS. Furthermore, following our statistical analysis, because no significant difference was observed among the respondents' profiles, we can assume the control group adequately represents the families in the pilot project.

→ *Women* (pilot project: 78%; control group: 83%) represent the largest proportion of respondents.

→ The majority of respondents were aged *40 or older* (pilot project: 56%; control group: 66%).

→ **On average**, the families interviewed had **two children**, both in the pilot project and the control group.

→ A certain divide was noted between less affluent and more affluent families. About half of the families had either a gross annual family income of *less than $30,000* (pilot project: 25%; control group: 33%) or *$100,000 or more* (pilot project: 20%; control group: 19%).

→ Less than a quarter of the respondents were *born in Canada* (pilot project: 25%; control group: 17%).

→ The majority of respondents have lived in Canada for between *five and 14 years* (pilot project: 63%; control group: 58%).

→ Most parents reported being *married or in a common-law relationship* (pilot project: 78%; control group: 83%).

→ More than half of the respondents had a *university* education (pilot project: 61%; control group: 52%).

→ The *CEMTL* is slightly more represented than the other institutions and is grouped under two sets of sectors (LT and SLSM sectors: 21%; PDI sector: 14%).

LT = Lucille-Teasdale

SLSM = Saint-Léonard and Saint-Michel

PDI = Pointe-de-l'Île

Theme 1: Modelling patient navigation

Significant tasks

Typical actions of patient navigation and their evolution

Psychosocial interventions, as well as adaptation and rehabilitation practices and their various functions, are gradually changing due to certain dilemmas and pitfalls, including the proliferation of stakeholders and apparatuses, the increasing complexity of cases and intersectoral dynamics. Patient navigation fits into this major trend as a typical, but also acute, case of a division of intervention work that reassigns its roles between the professional stakeholders and the parents and families who surround the users.

While we were going over the data and doing an emergent qualitative analysis, four dimensions emerged which we were able to group under two distinct themes.

The first theme concerns the subject of the intervention, with the network (RSSS) on one side and the family on the other. Patient navigators not only work with families, but also with and “on” the network itself, by breaking down barriers, obtaining services, securing various tools and using procedures available to them.

Network -- Family

The second theme concerns the types of actions based on whether they involve working “on” or working “with.” The expression “working on,” while it evokes an old-fashioned, authoritarian style of intervention, is used here to describe a position of exteriority in relation to the subject of the intervention. This means that when an individual is observed or assessed, the patient navigator’s role is that of an expert observing the situation. They work “on” situations. The same applies when they try to overcome entities and procedures beyond their control; they work on the system, trying to make it work as well as possible, looking for fast solutions and facilitators.

Working “with” the network is possible in situations where stakeholders and representatives of different systems come together to discuss and coordinate their efforts. Therefore, we are positioning network-related tasks as working “with,” since it is clearly different from actions that involve advocating for the interests of the user in order to obtain a service.

Working “on” -- Working “with”

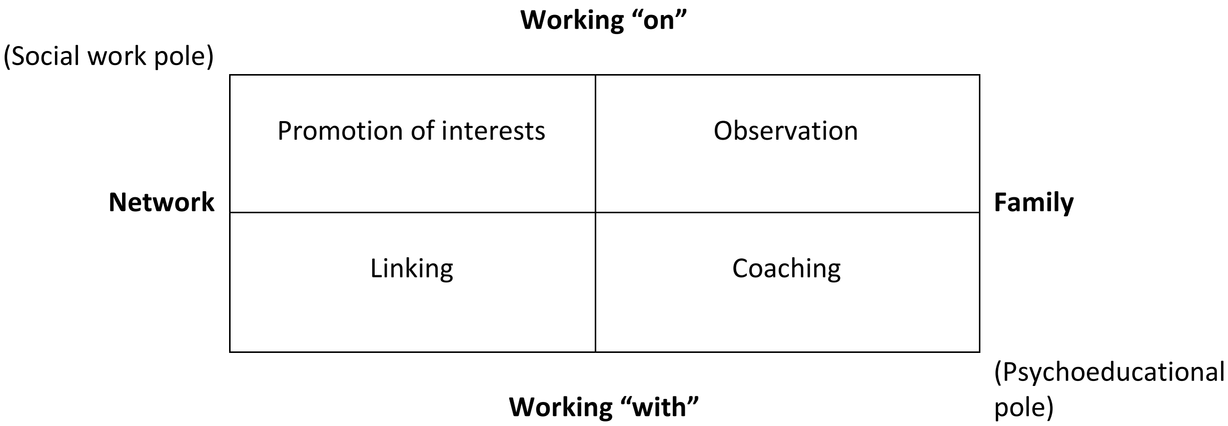
At each end of a third theme superimposed on the original two, we find poles of action that participants attribute to typical social work or psychoeducational work. In fact, we can show in a schematic that actions at the end of "working with the network" are tasks attributed to social work. As for "working with families," we find more actions attributed to a psychoeducational approach.

Social work -- Psychoeducation

Typology: The four dimensions of patient navigation

Based on the interviews and observations we conducted, four zones of action (**Figure 1**) make up the work and tasks of the patient navigator: observation/assessment, advocacy and promoting the user's interests, transfer of knowledge and parenting tools, as well as linking interventions and services.

FIGURE 1: THE FOUR DIMENSIONS OF PATIENT NAVIGATION



(Social work pole)

	Network	Family
Working "on"	Promotion of interests	Observation
Working "with"	Linking	Coaching

(Psychoeducational pole)

Observation/assessment: *"I'm observing the child in his natural environment"*

The observation and assessment of the child and family make up the first zone of action described by PNs. This zone refers to a style of practice that involves working "on" families as opposed to working "with" families, which we will address in the third zone of action we are proposing. It amounts to an initial appraisal of the situation, which will be updated as the therapeutic strategy of the child and the child's family evolves. It is also an opportunity to identify needs and realistic objectives to be worked on with the child and the family, and to prepare an intervention plan. This knowledge accumulated by PNs allows them to identify certain problems *in situ* and propose solutions anchored in daily life, which gives them the potential to succeed. However, this zone of action can come into conflict with the recognition of experiential knowledge that mothers and families have (e.g.

knowledge of the children and their particularities). In such cases, PNs tell us that they try to adopt a position of openness toward what is already "working" for the family.

Advocacy and promoting the user's interests: *"I'm the person who always has to push"*

Advocating on behalf of the family and promoting their interests with Quebec's Health and Social Services Network (RSSS) and other authorities (ministries, community organizations, schools, etc.) is another zone of action in the work of a PN. Indeed, a large part of psychosocial practice in the broadest sense involves mediating between institutions and users (Ravon and Ion, 2012), which is perhaps even more the case with patient navigators. PNs know "which doors to knock on." Families benefit significantly from their knowledge of the system, including its inconsistencies and administrative processes. It is common knowledge that there could be multiple reasons for not having access to public services, e.g. not knowing what services are available, knowing about them but not receiving them, not asking for them, and finally, not having them available (Warin, 2016). These are all avenues that PNs can explore as part of their work with families.

Transfer of knowledge and parenting tools: *"In the long run, the family can't rely on the PN to do everything"*

Another important zone of action we have documented in the work of a PN involves sharing knowledge with parents. A variety of expressions are used to equip parents with the tools they need to continue improving and learning, so that they can become "autonomous." One PN explained that that she teaches parents how to get their child to learn a word. From that moment on, parents are able to teach their child all the words they want. While this parental coaching offers numerous advantages for everyone, it tends to make parents more aware, expanding their knowledge of their child, of the diagnosis and of parenting in general, even though they didn't have all the resources required for specialized support. In times when the RSSS is overloaded, the potential to blame parents for a failure can be especially devastating. Accordingly, when intervention is aimed at "empowerment," the practice of equipping families reveals the relationships of power that come into play.

Linking interventions and services: *"I'm the bridge between the families and all other services"*

The concept of patient navigation is one of support; that is, adapting to situations based on needs. This means that a PN is largely responsible for coordinating care and services. These actions related to patient navigation are perhaps those that are the most familiar to all stakeholders interviewed, namely ensuring the continuity, consistency and complementary nature (Fillion *et al*., 2012) of the various interventions with children and their families. Many environments and organizations are involved in the daily lives of these children throughout their trajectories, such as family, daycare, school, doctor, intensive behavioural intervention (IBI) worker, occupational therapist, nutritionist, community resources, etc. While each has their own expertise and resources, this division of work may result in fragmentation, creating discontinuities, interference and even contradictions. In such cases, the PN attempts – not without difficulty – to discuss with the stakeholders involved, especially to develop an intervention plan/individualized service plan (IP/ISP) that can be updated in a coherent way.

These four main zones of action involved in patient navigation are typical of the practice, but in reality are never found in their pure state. Instead, they intersect, merge with and overlap one another. For example, the coordination of services is often closely linked to promoting the families' interests and their access to care (zones 2 and 4). However, it is a reading grid that helps us identify the main lines of reasoning behind patient navigation, in the sense that they are both general goals and primary aims (observe, transmit, defend, coordinate, etc.) that organize the action and daily tasks of these practitioners. Still, these dimensions alone do not summarize the work of patient navigators. As in many professional endeavours, certain tasks can be identified which fit the official reality of the profession, such as those we just mentioned. However, there often remain implicit, latent or unofficial categories of action: tasks that individuals perform in a grey zone close to the actual needs of their clients. We will see later which practices these involve.

Stakeholder perspectives

Family: Needs and expectations, ability of the PN to meet them, and success factors

General perception of family needs

These needs are already known within the RSSS, but the data collected largely confirms them. Interviewed families mentioned rapid and free access to a diagnosis and intensive behavioural intervention (IBI), as well as speech therapy, occupational therapy and nutritional services. Obtaining a diagnosis remains the starting point for care and services. The earlier a diagnosis is established, the more appropriate the interventions can be, in keeping with the logic of early intervention, which seems to have shown tangible results based on scientific discussions regarding ASD.

Following a diagnosis of ASD, IBI is what the network recommends. This is what the majority of parents want for their child. In addition to the issue of general access to IBI, a recurring theme is the inability to obtain this service in a timely manner and its connection with other institutions, particularly daycare facilities. Parents report that even if they do eventually qualify for IBI, wait list delays result in them accessing the service when their child is no longer eligible.

Another service cited by families as a top priority is speech therapy. As we shall see, the need for speech therapy services is closely linked to the parents' perceptions of their child's autism and communication skills. Children with ASD acquire language differently, and parents often have a strong desire for their child to communicate "normally." PNs will sometimes reframe parents' expectations regarding language, either in terms of the child's "natural" development or educational opportunities for language that do not require a speech therapist.

Among other needs that were named most often are occupational therapy and nutrition, two aspects of children's daily lives that often pose problems for parents. In the case of occupational therapy, it is the need for various adaptations in daily life, particularly to ensure the child's safety at home (e.g., keep the child from running away, control their emotions to avoid a crisis, etc.). As for nutritionist services, it is known that children with ASD present challenges at mealtimes due to inflexible dietary habits. Families also cite the need to access specialized educational settings to care for their child, since they do not always have a daycare or school that welcomes all children and has specialized staff.

Access to services and lack of access due to lack of knowledge

In their accounts, parents talk about their contacts with the RSSS and various departments, which can often be summarized as difficulties with communication and follow-up of their case. It is not uncommon to hear of unsuccessful attempts to reach a care worker or the inability to be referred to another person. "For me, it was my social worker. At one point, when I lost the spot at daycare, I wrote to her, called her, tried to contact her, but she didn't reply. At one point I got upset, thinking "Does she have a boss? Can someone reply to me? Is she dead? It's not normal. I was writing emails, lots of them, and figured that after a few weeks, someone has to respond. Even if she's no longer there, her emails need to be forwarded to someone who can help. Finally, she tells me that she isn't my social worker. I thought to myself "Well, that's pretty bad service." (Camila, mother)

Access to a contact person appears to be difficult, but also lacking is the ability to access services that are available. Parents do not know what type of care or services exist nor what is possible, which sometimes leads to the feeling that the network is intentionally inaccessible.

> “I was just disappointed that I wasn’t getting the whole picture, because I think the parent is the primary caregiver. I understand that they can’t just say ‘These are the services available’ and that the parents have to read everything. But as a parent, you get the feeling that you’re kept in the dark, and when things go wrong, you say ‘Ah, that service exists!’ But why didn’t you say so from the beginning? You wait until we’re exhausted and almost at the end of our rope before you say or do something. You know as parents, we don’t know our rights. When we don’t even know what services are available, we don’t know our rights. We don’t even know what we are entitled to.” (Camila, mother)

While research has already shown us that users must be able to clearly express their needs according to the terms of the services available in order to access them (Ouellet, Corbin-Charland and Morin, 2017), it becomes difficult to do so if people do not know what these services are. What’s more, it is often difficult for parents to identify these needs until they know the possibilities of responding to them.

Once a service is requested, long waiting periods characterize parents’ experience with the RSSS.

> “I was really exhausted that year. I saw myself as incapable, I didn’t have the means to move forward, to do something for my daughter. At the same time, I knew that a request was made to the CLSC and that I would have to wait for that as well. I would wait, and wait, and wait! I would get impatient waiting for services. There’s always a waiting list and delays for everything. If you want a service, any service, be prepared to wait.” (Amel, mother)

Parents lament the fact that an urgent situation or crisis is often required to prompt action and receive services.

> “Listen, I’m near the end of my rope because something has to give. I don’t know what to do anymore. When I asked about the diagnosis, that’s when they chose to speak to me. ‘Are there any services offered at the hospital? No!’ But when the person realized that things were going badly, she said ‘There is a service, but it’s really meant for emergencies and such.’ But because my daughter ran away and there was a real danger for her safety, it was a day hospital. (Camila, mother)

Also mentioned was the feeling of risking losing the services they already had if they complained too much:

> “That’s why I mentioned that when the parent has to rely on someone, they are powerless. There’s nothing you can do. It’s hard to say ‘I’m going over your head.’ You’re always afraid of losing what few services you can get. So, we keep quiet and suffer. But I don’t want to judge. I’m not saying everyone is like that. You can’t generalize.” (Camila, mother)

We refer to "lack of access due to lack of knowledge" to explain situations where target populations do not successfully receive the services intended for them (Warin, 2016). Such situations are what patient navigation seems to address most, including a family's need of a map of resources and services.

Variability of needs

Parents sometimes mention needs that correspond to specific PN tasks. While these tasks refer to the types of work we described earlier, it is risky to say which type of intervention is most valued, because the needs of families vary depending on the specifics of their situation, their basic parenting tools, access to other services, etc.

One need is commonly mentioned regarding lack of access due to lack of knowledge, and could be described as map-related, i.e. knowing the service options, how they're organized, how they relate to each other and how to access them.

> "No matter what question I ask, she's the one who calls the people involved so she can get back to me with an answer. That's what I found interesting because without her, I'd be lost. She guides me and helps me cut through the red tape." (Amel, mother)
>
> "I ask questions because I don't know my rights. I don't know which door to knock on. I can honestly say that the social worker helped me." (Wafa, mother)

The work of linking different services and tools is also an important need for families, who have little success when they try to do it themselves. "The most helpful part for me was when she talked to the school. I think that helps bridge the gap between the teachers and me." (Line, mother)

> "I suggested that it be a group meeting of all stakeholders. It's really hard to co-operate, meaning to make my needs heard, and to take that to the school, the CRDI and at home. It's a bit hard to work together." (Amel, mother)

Unlike other parents, here the mother reports that access to resources is not something she needs:

> "My PN has many resources. She's sent me emails several pages long with many, many resources, but in general, I don't think I need all that stuff. Of all the parents who've had kids with autism, I think I know a lot more than anyone else. I've done my research, I've observed my two children for years, naturally. I like to observe and analyze, so I think I know them much better than other parents. [The respite, resources and subsidies] don't really interest me." (Line, mother)

For some families, what is most valued is the useful and concrete, referring here to being equipped with the right tools and abandoning, for example, the emotional support a PN can provide to a parent.

> "Having a social worker to talk to or (*laughs*) tell my life story to doesn't interest me; I don't want to talk about my life. I want something concrete… someone who will really help me. As

> parents, we really need that help because we're shocked, you know? Especially at the beginning, having an autistic child is something we know nothing about. You always have to be by your child's side." (Wafa, mother)

While some especially appreciate learning new techniques and acquiring knowledge in order to care for their child themselves, others note that their position as parents prevents them from doing an effective job. Here they are referring to the PN's role as an expert and an external observer.

> "She can observe my child in the classroom. I can't do that. When mommy is there, my son behaves very, very differently." (Line, mother)
>
> "We start with behaviour. She observes me and gives me ideas on how to work with my son. To be honest, it doesn't help. Time and time again, when a child is with a parent, they don't want to do the work." (Wafa, mother)
>
> "Marilou asks me to do things. Yes, I'd like to try them, to work more with my daughter. But a single parent can't always work with their child." (Camila, mother)

The variability of families' needs in terms of specific interventions leads us to the second step of surveying them more specifically on this topic, then to the third step of proposing an ideal model that is flexible and adaptable to these needs.

Perceived role of the patient navigator and success factors

While parents' specific needs with respect to their PN vary, certain broad trends emerge regarding their perception of their PN's work, the ability of the PN to answer their needs, and the success factors surrounding patient navigation. These qualities include the PN's concern for the other person and their own profession, the fact that the PN takes on the role of both social worker and psychoeducator, the continuity of the relationship, and finally the creation of an alliance that shares professional and parenting knowledge, and demonstrates therapeutic realism.

Concern for others and their profession

Parents often exhibit the same qualities they appreciate or seek in a PN, namely having the child's well-being at heart and liking their profession. Sometimes, these two qualities can be even more important than expertise or experience.

> "She's someone who really loves her job. I'm telling you, from what I saw, she's serious about what she does and always gives 100%. She did everything she could for my daughter and was a major support for me." (Amel, mother)

> "She was wonderful! She adored my daughter and put a lot of love into her work." (Camila, mother)

> "When we know she is coming, we are happy because the mood in the house changes; we know that Milo is excited to see her." (Ricardo, father).

Wearing two hats

Two different training profiles illustrate the background of PNs in the pilot project: social work and psychoeducation. While some PNs in the RSSS may lean toward one or the other, we noticed that parents placed particular importance on a PN's ability to fulfill both roles.

> "So, that's when I got a phone call. It was a woman, a very nice person. What I especially liked, and I hope this becomes standard practice, is that she's trained in special education and wears both hats." (Camila, mother)

The role of the social worker is often summarized as "paperwork" by parents who see less value in it. However, those who have been able to benefit from subsidies or services as a result of this "paperwork" are grateful for the work of their PN. Therefore, the value attached to either of these two "hats" depends on the needs of the parents. However, many appreciate both roles being fulfilled at the same time.

Continuing relationship and maintaining contact

What appears to benefit parents is not only having a PN per se, but also keeping the person assigned to their case. Sometimes, the PN's presence quickly becomes essential, even if, paradoxically, their role is not clear to the parent.

> "But honestly, as I mentioned, her job is a little unclear to me. So far, I haven't been able to figure out exactly what she does, but as I said, I need her for my entire family. The whole family, honestly, not just for my daughter." (Amel, mother)

Assigning a PN to a person's case centralizes information and makes the process easier and faster. Continuity and reliability of the contact are important for parents.

> "I don't want to talk to 3,000 people, hear everything through word of mouth or answer endless questions from every direction. Everything is centralized. She gives me great service; when I contact her, I get answers right away." (Camila, mother)

Families become attached to their PN and often want the person to remain associated with their case even when they access other services. These experiences are consistent with the idea that families would like or should have a type of PN who supports them throughout the intervention process.

> “When I was assigned a woman from the CRDI-TED[7] for the services I needed, I said: “Oh, I really like Marilou [PN]. I have nothing against you, we can try it, it’s just that I’ve had different experiences and I love the way Marilou works.” (Camila, mother)

In the same way we speak of the contact role in communication studies to suggest that the interaction itself sometimes counts more than the content of the message, here we can confirm that it is the contact role of the PN that really counts, i.e. the very fact of having a PN, a person they can reach out to and can trust.

> “Even if it’s pouring down rain, I mean really, really pouring, she comes here! She comes!” (Ricardo, father)

As we will now see, this contact role may make the most sense when a clinical alliance is built between the PN and the family.

Building a clinical alliance

Building an alliance between parent and PN appears to be the key to successful patient navigation. This alliance is made easier thanks to a degree of “therapeutic realism” acquired through the PN’s experience in the field. A clinical alliance helps the parent and the PN build a relationship where different types of knowledge, both parental and professional, are recognized and shared.

The vast majority of parents seem to notice and value their PN’s field experience, which we believe improves their understanding of the issues they must face each day.

> “Since they already work with kids, they understand when parents talk about their problems. They put themselves in the parent’s shoes, and then they understand him. They really understand him. (...) (Camila, mother)

> “I think age matters a lot. With age, you understand what life is really like.” (Line, mother)

This improved sharing of expertise lies in contrast to the overbearing attitude adopted by some PNs, where there’s no room for negotiation. As a result, some parents complain that they can easily be accused of not co-operating if they question certain methods or objectives of a PN.

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[7] See note 6.

This experience in the field and the sharing of expertise go hand in hand with a dose of therapeutic realism. The goal is to improve the situation by correcting what is not working, without questioning everything, and adapting to the family's reality, which can change. Flexibility, resourcefulness and perseverance are essential.

> "Patient navigators say 'It's trial and error.' Well, we can try it, but if it doesn't work, we need to try something else." (Camila, mother)

The PN's perceptions of families' needs and issues with the practice

Division of tasks for intervention

Our discussions with PNs initially revealed a concern for the division of labour in intervention. PNs are central to this division of tasks among the various stakeholders inside and outside the network, as well as the parents. In line with previous studies (Fillion *et al.*, 2012), the navigation role seems to target certain objectives, including the following:

- ***Complementarity***: This objective aims to avoid duplicating services and maintain those that are already working: *"First I look at their needs. If they already have a psychoeducator and things are going well with that person, I examine other approaches. I ask the parents whether they are satisfied with everything being done."* (Marilou, PN)

- ***Consistency and integration***: This objective aims to ensure that interventions feed off and reinforce each other: *"If I'm working on a goal at the patient's home, I'd like the school to do it, too. It's difficult to have that level of co-operation. The child ends up going to school but can't make use of the skills learned at home. I have clients who started to communicate verbally, but at school you won't hear them utter a single word. The child can talk, but you need to put the right tools in place."* (Suzanne, PN)

- ***Full coverage***: This objective aims to meet the family's needs as much as possible and identify gaps in service: *"The goal is to contact everyone, sit down together and say 'What are you working on with the family? How about you?' Then we go see the parents and ask 'Does this meet your needs? Are there other needs we haven't addressed? Who's taking care of them?'"* (Marilou, PN)

These objectives can be achieved through a service plan that takes into account the specifics of social work and psychoeducation, the disciplinary fields involved in training PNs:

> "For me, another potential solution would be to have two people, a social worker *and* a psychoeducator, available for each case. That way, if they don't need a psychoeducator, they won't need to wait another three or four months. At least when they receive the service, they would be better prepared and would get what they really need." (Marilou, PN)

We will see that complementarity of training is a recurring issue brought up by PNs. The experience of PNs teaches us that while intervention practices are divided into the four main dimensions we identified, they are deployed in line with the objectives and aims of complementarity, consistency and coverage.

Reframing expectations and translating needs into services

Reframing expectations is an essential aspect of a PN's work and a condition for successfully managing situations. Families meet with PNs to deal with a common situation, but may have as many expectations as there are possibilities. To meet the family's needs, one of a PN's first tasks is to understand these expectations.

> "Sometimes it's hard. We have parents who have very unrealistic expectations of their child." (Rachel, PN)

> "What happens sometimes is that they tell us 'I don't really need a psychoeducator, I'd like to have a social worker.' Or they tell me what their needs are and I say to myself 'Yeah, it's true that a social worker would be better than me.' But sometimes I'm really the person in the best position to take care of them. It's just that there's a lot to sort out at the beginning." (Marilou, PN)

Once needs and expectations have been assessed, a reframing operation is often necessary, whether to translate the family's needs into the services required, or to identify the different stakeholders involved.

> "Sometimes I have to tell them 'I'm sorry but that's not my job, I'm not here for that.' So I often adjust parents' expectations of my role. Another challenge is that parents are surrounded by a host of different people and don't know who does what. They have a hard time understanding our roles and tasks, so that's why I love giving parents a copy of the service plan. Every problem, goal and approach is written down, in addition to who is responsible. (Karine, PN)

Here we see the PNs providing a map of the services, a preliminary step to navigating the network. Speaking of this framing and reframing of expectations and their translation into the right services, the PNs also tell us that their actions are based on usefulness to the family:

> "I wanted to make sure we were really targeting a need that was useful and realistic for the family. It could be anything, independence for example: going to the bathroom, eating, eating with a utensil, more independently, or eating a variety of foods because the child is stubborn. It could also be behaviours, for example children who are much more unruly, who refuse to follow instructions or have more difficulties at the beginning of the school year." (Suzanne, PN)

Although this last account describes a more direct intervention related to habilitation/rehabilitation practices, PNs can also work on "useful and realistic" needs such as respite services, subsidies or services available in the community.

Our analysis indicates that practitioners perceptions of parents' needs, along with their perceptions of their own role, interact in many ways with the needs and expectations expressed by the families, leading us to conclude that there are various conditions for success when it comes to patient navigation.

Issues with the practice

Finally, anchoring the practice with the needs and expectations of the families, and then translating them into available services, takes place in the context and framework of certain issues related to patient navigation.

> "There are parents who think we're not doing enough, that we need to go further, but there's no shortage of children who need services. There's what we can offer and what they should get. It's two different things: needs and available services." (Rachel, PN)
>
> "I could have stayed with certain families for years, but then there are always other needs." (Suzanne, PN)

PNs mention several issues in their practice, especially concerning broader issues within the RSSS. While the glaring and already well-known issues come up often, such as the lack of workers and services, long waiting lists, the time-consuming task of compiling statistics, and high staff turnover, PNs also tell us about conditions that are more specific to their practice.

Arriving after a diagnosis and the paradox of waiting for services

PNs report they are too late in providing services for families when they are really needed. Families often wait a very long time to access services, which can lead to anger and mistrust. In addition, they are assigned a PN while hoping for an IBI, which leads to disappointment.

> "There's no doubt that families are very, very dissatisfied with the services provided. It's obvious. They wait and wait and it just makes no sense. Then, when we finally arrive, the first ones assigned to their case, there's no IBI. Families are told that what's effective is an intensive intervention, meaning 18 hours a week. So, when I arrive, the family has already been waiting at least a year. I often get frustrated because they expect it to be more intensive. Yes, they're happy I'm there because they need me quite often, but they're a bit frustrated. It's hard for me to earn their trust. They say things like 'Are you just going to evaluate us again and disappear? Is something going to actually happen this time?' It often happens that parents are reluctant or there's a lot of pain, a lot of frustration with the services." (Marilou, PN)

Frequently mentioned was the paradox between a family's expectations of the initial service and the fact that this service, the patient navigator, does not always meet these expectations. The various stakeholders are confronted with the fact that there is a waiting list for a mechanism perceived as a way to shorten the waiting list (i.e., patient navigation).

> “What’s ironic is that there’s a waiting list to reach me. Ideally, as soon as they’re on the waiting list for access, there should always be someone like me. That would be ideal and really make sense. Because what happens is they wait a year, then I show up and say ‘It’s for people waiting for a first service.’” (Zoé, PN)

The main argument raised for reducing the wait for a patient navigator is the negative consequences of this wait on the child’s well-being.

> “If the child is taken care of as soon as they are diagnosed, we’re maximizing that child’s chance of success. What happens is the parents are less stressed, they know what to do, they establish a relationship of trust with someone, who guides them in the right direction. The child progresses at their own pace, but at least they make progress. And all the partners involved, well, they have a resource person they can rely on.” (Suzanne, PN)

Scale and characteristics of the caseload

Very often, the size of the caseload is mentioned. This varies depending on the CIUSSS and their division of programs and services, but it usually numbers around 50 families.

> “The caseload’s high. Personally, I’d like to have around 10 kids and be able to see them every week. That would be ideal. But that’s not what happens.” (Marilou, PN)

Faced with this, workers in the RSSS use different strategies to put together an adequate caseload by playing on the combination of criteria for cases (urgency, complexity, etc.), including categories in the “Cadre d’analyse de la charge du travail” (analytical framework for the workload). (OTSTCFQ, 2009).

The extent of the caseload in terms of qualifying cases (difficult, complex, etc.) is also frequently mentioned. Depending especially on the neighbourhoods and their socioeconomic conditions, we find fairly heavy caseloads that may involve disadvantaged and vulnerable families. Therefore, the social aspects of a family’s situation are closely linked to health and therapeutic aspects.

> “The families are very, very disadvantaged. When you have a child with ASD, it requires a tremendous amount of organization. It costs a lot of money to sign them up for activities, adapt their home to their needs, buy the things they need, and so on. It’s not easy. I worked in an area that was very, very disadvantaged in terms of financial resources, so they don’t have enough income to be able to cope with everything that it requires.” (Claude, PN)

Another factor that illustrates the caseload of PNs is the very high percentage of families who are recent immigrants to Quebec. According to administrative data, most of the families involved in the pilot project have been in Quebec for between five and 15 years. In the sample of participants interviewed, seven out of 11 families were immigrants. This aspect seems to have three major implications:

1) Carry out interventions using interpreters, translators, multiple family members or inventive solutions.

> "I didn't have any problem with Mandarin or Arabic, but I have a mother who only speaks Russian and I can't find an interpreter. They only have two, but they were on vacation all summer, so I couldn't get one. Finally, what we did was ask this woman's friend, who speaks English and Russian, to translate for us. So now we speak English and I use Google Translate on my phone so we can communicate." (Rachel, PN)

2) There is strong correlation between the well-being of the child and family and their level of integration into society, and therefore the status of their application.

> "Sometimes they call me and say 'I'm applying for citizenship. What papers do I need to fill out?'" (Rachel, PN)

> "They don't have a network, so they have to find help elsewhere." (Rachel, PN)

3) Finally, there is a great need for cross-cultural intervention around a shared understanding of diagnoses, interventions and social practices.

> "The model of the couple is different. The families are from different cultures, and the emotions are not addressed on a daily basis." (Adrienne, IP)

> "I've had several families tell me that God would not have given them a child if they were unable to take care of it. So having the child be supervised was like a badge of shame for them. It was perceived as an embarrassment by other family members and their friends. Daycare, however, is acceptable, so we try to send them to daycare more often, so that the mother gets a break during the day. Or we assign the child to an activity, so the mother can rest during that time." (Rachel, PN)

Of course, these conditions sometimes go hand in hand (i.e., disadvantaged status and recent arrival in Quebec) and are intertwined in the family's situation and, by extension, the issues surrounding patient navigation.

> "Everything tends to be interrelated. I have a mother who's a compulsive hoarder. I have mothers with depression. I have people with personality disorders, from poor backgrounds, who are recent immigrants. I even do immigration-related things." (Rachel, PN)

Objectives that are explicitly implied

Various effects of patient navigation emerge as a result of tinkering and negotiation on the part of PNs. What they are asked to do, given the reality and needs of a particular family, contrasts with the clinical leeway they are given. Navigators seem aware of such tasks and do them implicitly as "no-brainers." Our observations in the field revealed different roles that PNs take on in direct response to the needs and reality of families, even though these roles have never, to our knowledge, been explicitly assigned to this type of practice. Action ultimately fills in the gaps; patient navigation is part of a long tradition of psychosocial intervention, which has proposed since its inception to “mend the social fabric” (Ravon and Ion, 2012). The practice of patient navigation, in the cases documented here, seems to mold itself to certain informal but common needs that families have, particularly surrounding issues of immigration and integration into the host society, as well as aspects such as legal matters. It is this flexibility of the practice that seems to give it its richness, i.e. its ability to adapt to the needs and realities of the families, in particular by drawing on the four zones of action that we have mentioned.

Diagnostic socialization

Other tasks end up effectively identifying patient navigation in their accounts of intervention and the experiences of families. First of all, we know that a key moment for families is the announcement of a child’s diagnosis, which can be difficult for them and be seen as a major loss. What’s more, each parent does not necessarily react the same way. Following this announcement, for the family there is a period of varying acceptance and negotiation with this new reality. In the material studied, patient navigators often play a key role in this process. Both the families and practitioners told us that this is an important moment in their shared work.

In sociology, socialization refers to the processes by which we learn the norms, values and attitudes that allow us to be part of a particular group. In our study, we note that patient navigators play a major role in what can be called the diagnostic socialization of families. They familiarize parents and siblings with the concepts of autism and/or intellectual disability, in particular with the condition’s permanent nature, which cannot be “cured.” They introduce the family to a certain vocabulary they can understand, for example the metaphor of having “different eyeglasses,” or for the parents, having to give up the idea of having a “perfect child.”

Emotional support for parents

When a family receives a diagnosis of ID-ASD-GDD, a genuine obstacle course begins, one that often goes hand in hand with financial woes, stress, anxiety, fatigue, marital problems and social isolation. Patient navigators position themselves as emotional and moral supports in the face of these changes and hardships: “It takes someone to help parents get back on their feet!” The psychological well-being of the parents, who are often fully dedicated to their child, frequently takes a back seat. This is something the navigators try to remedy.

One thing that seems crucial to PNs is to support the parents in a holistic way and involve the entire family. The implicit idea is that working in the child’s interest also means working on and with the parents and siblings. This is a practice that appears to be official and accepted for some, while flying under the radar for others, as it is outside their job descriptions.

> “I really take care of the parents a lot more, because I have the educator who works on behavior and rigidity. I have the psychoeducator who does a little of the same, who also evaluates. I have

> the speech therapist who works on language, then the occupational therapist who works on sensitivity and nutrition. So we have these four who take care of the children a lot, and there's not really anyone who takes care of the parents. So I've really taken on that role, because I have a lot of parents with mental health issues. I have a lot of... neglect, or abuse, and so on, or simply that they don't know the system, they need a subsidy, they need to be referred to services. So that's really the role I play slightly more with parents." (Rachel, PN)

> "Well, I manage it to some extent, meaning I'm not supposed to manage it, but at the same time I can't ignore it, and it affects the entire follow-up. I have a mother – this will be the fifth time I've seen her – and we still haven't talked about her daughter. Barely. Because she constantly talks about her problems and seems to be depressed with a panic disorder... She has anxiety attacks, she has panic attacks, and it's very, very, very distressing for her. So we talk about it, because she's so overwhelmed by it that I'm unable to... We talk a little bit about her child, but it's very difficult." (Adrienne, IP)

> "And that's another thing. Often the families who had several children were already asking me for advice on the other children, so I found myself doing some intervention..." (Suzanne, PN)

They also talk about respecting the limits and refusals of families, with a view to building a therapeutic alliance and avoiding coercion.

> "I try to be understanding for real, I put myself in their shoes, I would be angry too. I try to be understanding, and then get them to look forward. I'll say 'Well we're here to work.'" (Marilou, PN)

> "Ideally, we should always go there at least once, to their home, to see the environment. It helps us when we do our social functioning assessment and all that. But if the family doesn't want it, we shouldn't force them." (Alexandra, PN)

Managing expectations and a lack of services

The distress of parents stems in part from the lack of services, the endless waiting lists, a lack of information on existing resources, as well as the high turnover rate of PNs. One of the most interesting roles implicit to patient navigation, but also the most paradoxical, is to alleviate this waiting period and the lack of services. While one of the initial goals of ID-ASD-GDD patient navigation was to reduce waiting lists by making it easier to refer patients to the right services, this goal has actually transformed into a stopgap measure for this wait. In the interviews, PNs clearly stated that one of the purposes of patient navigation is to "find a small service while waiting for the list to clear," especially in the community. This latent role of the patient navigator illustrates a way of working that "copes with" the wait, the gaps in services, and sometimes even the lack of support.

Preparing for future interventions

Closely related to these tasks implicit to patient navigation is the work of preparing the family and the child for upcoming interventions. In keeping with diagnostic socialization and managing the lack of services, PNs are involved in keeping families informed and managing their expectations when they are on the verge of accessing much-needed intervention. Intensive Behavioural Intervention (IBI) is an approach that requires many hours of intervention each day by a specialist, along with a great deal of parental involvement. Very few spaces are available in the public system. In our interviews with patient navigators, we were told that IBI is more likely to be successful when parents are prepared and involved. The PNs also reframed certain wishes of the families, particularly with regard to speech therapy services, which are in high demand but not always necessary according to them, as well as nutrition services, which are rarely available in the public system but the families identify as crucial. So once again we see this role of mediating between the families and the system.

Areas of consensus

Integrating the views of families and PNs is illustrated more clearly in the ideal model presented at the end of this report. In the meantime, here are the areas of consensus that have emerged so far.

The various stakeholders appear to agree on the fact that patient navigation is more likely to succeed if it includes the whole family, is built on reliability and mutual trust, and if the PN agrees to play the role of both social worker and psychoeducator. They also agree that it is preferable to set realistic goals in the context of a therapeutic alliance.

On the outside, patient navigation also seems to work best when the definitions of the situation, needs and related services are the same for parents and PNs.

Theme 2: Effects of Patient Navigation

Satisfaction with each type of navigation

Based on the important tasks of PNs identified in the various interviews, along with their classification into four dimensions, we designed the phone survey with the aim of assessing the satisfaction of families vis-à-vis the actions taken by their PN, as well as the PN's ability to fulfill the needs inherent to each of these dimensions.

Table 9 shows the structure of the survey based on the categories identified in the first phase of the qualitative analysis.

TABLE 9: STRUCTURE OF TELEPHONE SURVEY

Dimension	Key excerpts	Survey statements
Observation/Assessment	*Visit the home to observe the child, their daily life and behaviour.* *Identify needs and objectives to work on.* *Prepare an intervention plan.*	My PN visited my child at home to observe their daily life, identify their needs and goals. My PN prepared and provided me with an intervention plan for my child.
Advocacy and promoting the user's interests	*Knows which doors to knock on.* *Knows the system.* *Takes care of obtaining services.* *"Fights for me."* *Helps me get respite, subsidies, fill out forms (adapted transportation, Family Support Program, diapers, summer camps, etc.).* *Helps me find adapted daycare, goes with me on visits.* *Helps me in my efforts.* *Tells me about available resources, e.g. community resources.*	My PN knows where to go to obtain services such as respite, subsidies, adapted transportation, etc. My PN tells me about the resources available in my area, through organizations and associations. My PN helps me with the various steps I need to take for my child (e.g., visiting daycares, finding a summer camp, etc.).

Dimension	Key excerpts	Survey statements
Transfer of knowledge and parenting tools	*Teaches me how to work with my child (e.g., communication).* *Shows me how to teach my child things (e.g., sleeping, eating, toilet training).* *Gives me tips for everyday life.* *Gives me ideas.* *Explained the diagnosis to siblings.* *Supports parents.*	My PN gives me tips and methods for dealing with everyday life, for example, sleeping, eating, toilet training. My PN teaches me how to work with my child and teach them new things. My PN has intervened with my other children or my partner to inform them of my child's diagnosis or to explain it. My PN supports me as a parent, listens to me and helps make my life easier.
Linking interventions and services	*Coordinates care and services.* *Acts as a liaison between my family and the daycare/school.* *Organizes meetings with other PNs.* *Coordinates school registration and liaises with the school team.* *Implements an individualized service plan (ISP).*	My PN coordinates the various types of care and services my child receives. My PN acts as a link with other PNs involved with my child, for example, she organizes meetings. My PN has developed and provided me with an individualized service plan that includes outside partners, such as the school.

Putting family satisfaction, response to needs and perceptions of waiting times in context

Summary of response to family needs (survey)

Respondents were asked a series of questions about 12 targeted intervention practices grouped under four dimensions. They were asked to indicate how much they agreed that each of these practices was successful in meeting their family's needs. For each item, respondents were asked whether they strongly agreed, somewhat agreed, somewhat disagreed or strongly disagreed.

Calculation of response rates to needs by practice and dimension

For each practice, a **rating of how well the needs were met** was calculated. Respondents were first asked how much they agreed that each of the targeted practices was successful in meeting their family's needs. A score was then assigned for each choice of answer (0 = strongly disagree, 1 = somewhat disagree, 2 = somewhat agree, and 3 = strongly agree). The sum of the scores was then divided by the number of respondents and presented as a percentage.

The rating of response to the needs of a dimension is a weighted average of the rate of response to the needs of all the practices that make up the dimension.

The rating of response to these practices was compared between subgroups of respondents (categorical variables) and analyzed according to variables that reflect their profile (some socio-demographic variables and whether or not they had an assigned PN in the pilot project).

The results are presented in the form of a table highlighting statistically significant differences between the respondents' profiles, at a confidence level of at least 95%. These differences are indicated by an asterisk (*).

An analysis of variance (ANOVA) was done for subgroups with more than two categories, and t-tests were done on independent samples for variables with two subgroups.

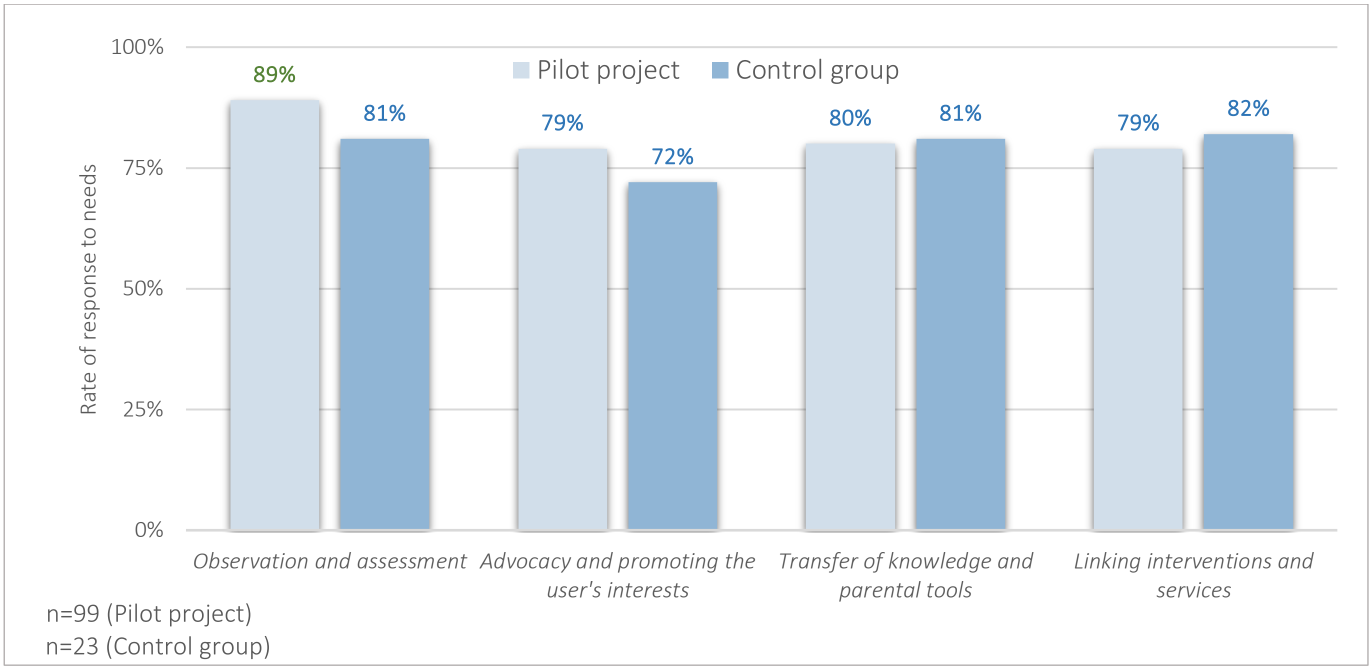
The "*r*" statistic for analysis of variance, the eta-squared index (η^2) for t-tests, as well as Cramer's V, were then calculated to show the size of the effect (Cohen, 1988), i.e., the strength of association between the two variables.

Only differences with an average** or large*** effect size (strength of association between the two variables) were retained.

The following results are a summary of the indicators grouped by dimension and presented as averages out of 100 (response rate to needs), which should be interpreted as follows:

82.51 to 100.00%	=	Strongly meets the needs (green)
50.01 to 82.50%	=	Meets the needs (blue)
16.51 to 50.00%	=	Slightly meets the needs (orange)
00.00 to 16.50%	=	Does not at all or almost never meet the needs (red)

Figure 2: Summary of response to needs for each dimension



→ Overall, in **Figure 2**,[8] respondents felt that the practices meet their families' needs (pilot project: 79-89%; control group: 72-82%).

→ For respondents, only one dimension of practice stands out more than the others in the pilot project. The "observation and assessment" dimension (pilot project: 89%) is the only one that would have largely met their needs.

→ No significant difference between the two groups of respondents (pilot project and control group) was observed during the statistical analysis. As a result, we can **hypothesize that the control group receives a service offer similar to that of the pilot project**.

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[8] Reminder: The rate of response to needs for a dimension is a weighted average of the response to needs for all the practices that make up the dimension.

TABLE 10: RATE OF RESPONSE TO NEEDS BASED ON RESPONDENTS

Weighted average rate of response to needs across all practices based on respondent profile

		Pilot project	
		n	%
Total		**99**	**81%**
Sex	Male	22	86%
	Female	77	79%
Age group	Under 25 years	1	97%
	25 to 29 years	4	74%
	30 to 34 years	19	84%
	35 to 39 years	19	82%
	40 to 44 years	34	78%
	45 years or over	22	81%
Number of children at home	1 child	24	84%
	2 children	43	80%
	3 children	22	75%
	4 children	7	86%
	5 children	2	100%
	6 children	1	85%
Gross annual family income	Under $30,000	23	79%
	$30,000 to $39,999	12	87%
	$40,000 to $49,999	11	85%
	$50,000 to $59,999	9	82%
	$60,000 to $69,999	9	79%
	$70,000 to $79,999	3	90%
	$80,000 to $99,999	8	84%
	$100,000 or over	19	74%
Born in Canada	Yes	25	78%
	No	74	81%
Marital status	Single	9	80%
	Married or common-law	76	82%
	In a relationship (with no marital status)	2	85%
	Separated or divorced	11	74%
Education	Primary (7 years or less)	3	81%
	Secondary (general or vocational training (8 to 12 years))	19	88%
	College (pre-university training, technical training, certificate, certification or diploma)	16	78%
	University (traditional courses, certificates, diplomas, undergraduate, masters or doctorate)	59	79%
Sector	CCSMTL	13	76%
	CNIM	12	83%
	CCOMTL	14	80%
	CEMTL (LT and SLSM)	26	83%
	CEMTL (PDI)	17	85%
	COMTL	17	75%
Control group	N/A	**23**	**79%**

- → The rate of meeting needs (for all practices) for all respondents (**Table 10**) is 81%.
- → Although this rate (81%) is consistent with the fact that respondents felt all practices meet their needs (from 50.00 to 82.50%), this value is at the upper limit of this interpretation. In addition, although this result is not significant, several subgroups of respondents (numbering more than five) felt that the practices as a whole meet their needs to a large extent, including:
- → *Men* (86%)
- → Ages *30 to 34 years* (84%)
- → *One child only* (84%) or *four children* (86%) at home
- → Gross family income of *$30,000 to $49,999* (85-87%) or *$80,000 to $99,999* (84%)
- → Highest level of education: *secondary* (88%)
- → CNIM (83%), CEMTL (LT and SLSM) (83%) or CEMTL (PDI) (85%) sector
- → No rate corresponds to meeting few needs, almost no needs or no needs at all.
- → Following the statistical analysis, none of the variables in the table significantly influenced the rate of response to needs.

Summary of overall satisfaction (survey)

In addition to the 12 questions specifically concerning the response to their needs (practices), respondents were asked a question regarding overall satisfaction:

> *"Overall, are you very, somewhat, not very, or not at all satisfied with the response to your family's needs by the practitioners from your CIUSSS?"*

As with the summary of response to families' needs, the results are presented in terms of overall satisfaction rates.

The overall satisfaction rates should be interpreted as follows:

82.51 to 100.00%	=	Very satisfactory (green)
50.01 to 82.50%	=	Fairly satisfactory (blue)
16.51 to 50.00%	=	Barely satisfactory (orange)
00.00 to 16.50%	=	Not at all satisfactory (red)

TABLE 11: OVERALL SATISFACTION RATE BASED ON RESPONDENT'S PROFILE

Overall satisfaction rate with the response to family needs based on the respondent's profile

		Pilot project	
		n	%
Total		**99**	**73%**
Sex	Male	22	82%
	Female	77	71%
Age group	Under 25 years	1	66%
	25 to 29 years	4	66%
	30 to 34 years	19	75%
	35 to 39 years	19	75%
	40 to 44 years	34	73%
	45 years or over	22	71%
Number of children at home	1 child	24	80%
	2 children	43	68%
	3 children	22	68%
	4 children	7	85%
	5 children	2	100%
	6 children	1	100%
Annual gross family income	Under $30,000	23	69%
	$30,000 to $39,999	12	78%
	$40,000 to $49,999	11	75%
	$50,000 to $59,999	9	85%
	$60,000 to $69,999	9	62%
	$70,000 to $79,999	3	89%
	$80,000 to $99,999	8	75%
	$100,000 or over	19	70%
Born in Canada	Yes	25	74%
	No	74	73%
Marital status	Single	9	74%
	Married or common-law	76	74%
	In a couple (with no marital status)	2	83%
	Separated or divorced	11	63%
Education	Primary (7 years or less)	3	66%
	Secondary (general or vocational training (8 to 12 years))	19	84%
	College (pre-university training, technical training, certificate, certification or diploma)	16	68%
	University (traditional courses, certificates, diplomas, undergraduate, masters or doctorate)	3	71%
Sector	CCSMTL	13	66%
	CNIM	12	72%
	CCOMTL	14	74%
	CEMTL (LT and SLSM)	26	71%
	CEMTL (PDI)	17	90%
	COMTL	17	64%
Control group	N/A	**23**	**74%**

→ **Table 11** indicates that the overall satisfaction rate (regarding the response to their family's needs) for all respondents is 73%.

→ To a lesser extent, as with the summary of the rate of response to the needs presented above, although this rate (73%) is consistent with the fact that the response to their family's needs is fairly satisfactory (from 50.00 to 82.50%), several sub-groups of respondents (number more than five) consider it to be very satisfactory, including:

- *Four children at home* (86%)
- Gross family income of *$50,000 to $59,999* (85%)
- Highest level of education: *secondary* (84%)
- *CEMTL (PDI)* sector (90%)

→ None of the rates shown indicate that the family's needs were met with little or no satisfaction.

→ Following the statistical analysis, we observed that none of the variables in the table have a significant influence on the overall satisfaction rate of the respondents.

Access to services (survey)

Given the bias in the administrative data of the five CIUSSS regarding access to services, a few questions in the survey concerned delays and the respondents' perception of the length of these delays.

We first asked respondents about the delay between the first request for service and the delivery of the service. The question we asked was as follows:

> *When you contacted your CIUSSS for the **FIRST TIME** to request care or a service for your child, approximately how many days went by between this request and this care or service? We are referring here to an appointment with a social worker, a rehabilitation follow-up, etc.*

TABLE 12: ACCESS TO FIRST SERVICE

Delay in accessing 1st service	Pilot project	Control group
Average	254 days	307 days
Minimum	1 day	2 days
Maximum	1,080 days	2,160 days
Standard deviation	268 days	471 days
Number of respondents	99	23

→ On average (**Table 12**), respondents reported waiting more than 250 days between their first request and the service being delivered (pilot project: 254 days; control group: 307 days).

→ Since the standard deviation between the groups is relatively wide (pilot project: 268 days; control group: 471 days), it is practically impossible to observe a significant trend between the groups or even between the respondents in this form. Consequently, no significant difference between the two groups of respondents (pilot project and control group) was observed during the statistical analysis.

Table 13 looks at the same delay between the first request for service and the delivery of the service, but here the data is grouped and presented in terms of months (30 days/month). In addition, respondents were asked a second question regarding their perception of this delay:

> *Do you consider the time between your **FIRST** request and the delivery of this care or service to be very short, short, average length, or very long?*

TABLE 13: ACCESS TO FIRST SERVICE (CONTINUED)

Delay in accessing 1st service (cont'd)		Pilot project		Control group	
		n	%	n	%
Delay between first request and delivery of service	Less than 3 months	39	39%	8	35%
	3 to 5 months	8	8%	6	26%
	6 to 11 months	38	38%	5	22%
	12 months or more	14	14%	4	17%
Total		**99**	**100%**	**23**	**100%**
Perception of delay between first request and delivery of service	Very short	3	3%	-	-
	Short	14	14%	1	4%
	Average	27	27%	11	48%
	Long	23	23%	5	22%
	Very long	32	32%	6	26%
Total		**99**	**100%**	**23**	**100%**

→ As mentioned above, it is practically impossible to observe a significant trend due to the wide standard deviation, i.e. the large variability and range of results between the respondents (pilot project: 268 days; control group: 471 days).

→ However, we observed that for the pilot project group, the majority of respondents said they waited either less than three months (39%) or between six and 11 months (38%). Unfortunately, it was impossible to verify whether this is due to the priority code on the application (bias in administrative data).

→ Approximately half of respondents consider this delay to be *long* (pilot project: 23%; control group: 22%) or *very long* (pilot project: 32%; control group: 26%), and most of the others consider it to be *average* (pilot project: 27%; control group: 48%).

→ The Chi-square test (χ^2) was used to verify whether there is a relationship between these categorical variables, and no significant difference was observed in the statistical analysis between the two groups of respondents (pilot project and control group).

Respondents were asked two more questions regarding other requests for services made to their institution:

How many other requests for care or services have you made to your CIUSSS?

Do you consider the average delay between your other request(s) and the delivery of this care or these services to be very short, short, average length, or very long?

TABLE 14: ACCESS TO ADDITIONAL SERVICES

Access to additional services		Pilot project		Control group	
		n	%	n	%
Number of service requests following first request	No other request	36	41%	8	42%
	One other request	17	19%	3	16%
	Two other requests	16	18%	5	26%
	Three other requests	12	14%	1	5%
	Four other requests	4	5%	1	5%
	Five or more requests	3	3%	1	5%
Total		**88**	**100%**	**19**	**100%**
Perception of the delay between other service requests and their delivery	Very short	1	2%	1	9%
	Short	8	15%	-	-
	Average	16	31%	1	9%
	Long	14	27%	3	27%
	Very long	13	25%	6	55%
Total		**52**	**100%**	**11**	**100%**

→ Less than half of the respondents (**Table 14**) did not request another service following their first request (pilot project: 41%; control group: 42%).

→ Among those who had made more than one request in total, more than half considered the delay between new requests and their delivery to be *long* (pilot project: 27%; control group: 27%) or *very long* (pilot project: 27%; control group: 55%).

→ No significant difference between the two groups of respondents (pilot project and control group) was observed in the statistical analysis.

→ It is important to note that we are assessing a perception of the length of the delay here, given that we could not assess it using the administrative data. Although we can hypothesize that the delay between other requests for services (following the first request) and their delivery should have been shorter, it is difficult to confirm or deny this based on perception without this information. However, we can still raise questions about the fact that more than half of respondents consider these delays to be long or very long, as previously mentioned.

The lack of a significant difference between the pilot project and the control group is a result in itself, and can be interpreted using several different approaches. First, as was suggested to us by the groups concerned, this probably means that the PNs assigned to the pilot project did not do anything “differently” than usual, and that the RSSS already encourages patient navigation that satisfies families in general. This lack of a difference also confirms and validates that cross-referencing the interviews with the survey data gives us a good picture that allows us to generalize, since we can conclude that the practices are very similar. We were also told that it is difficult, if not impossible, for the CIUSSS to attribute any change in their internal statistics to the specific existence of the pilot project, or simply to the fact that it involved the addition of a position in itself.

Theme 3: An ideal emerging model of patient navigation

Theme 1 enabled us to identify the significant practices of the patient navigation and organize them into four key dimensions: observation/assessment, promotion of the user's interests, linking and parenting tools.

Theme 2 provided us with information on the level of response of these significant practices to the needs of families, their overall satisfaction with the practices of patient navigation, as well as their perception of the delays in accessing the services.

Theme 3 aims to combine these first two themes, i.e., the significant practices identified in Theme 1 and their level of importance and response to the families' needs explored in Theme 2. In this way, by cross-referencing the data from the first two themes, we can create a visual portrait of the practices based on the importance given to them by the families and the level of response to their needs. As a result, we can target the practices to be given priority, so that the patient navigation being studied can best respond to the realities of the families concerned.

Chart of prioritization of practices

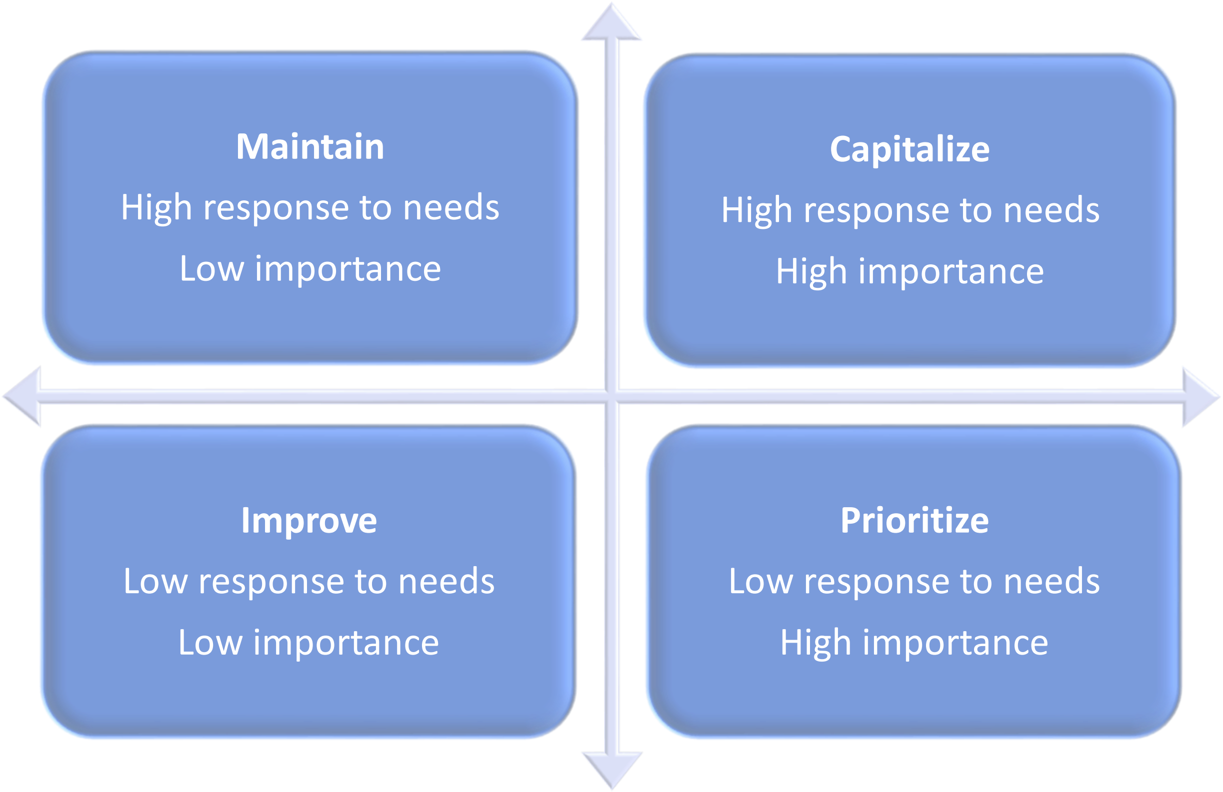
Methodology

In this section, the 12 targeted intervention practices are plotted on a scatter chart. This type of chart makes it possible to compare the performance of the practices and identify priorities for action to improve families' overall satisfaction with the navigation services they receive.

All the practices are plotted based on the following:

- **Vertical axis**: The rate of response to families' needs (top of chart: highest rate; bottom of chart: lowest rate). The horizontal line bisecting the vertical axis represents the weighted average of the rate of response to needs across all items.
- **Horizontal axis**: The index of importance calculated based on the degree of correlation between the rate of response to the needs of a practice and its degree of influence on the respondents' overall satisfaction with the range of services they receive (right side of chart: high correlation; left side of chart: low correlation). The vertical line bisecting the horizontal axis represents the weighted average of the index of importance for all items.

FIGURE 3: EXPLANATION OF QUADRANTS



- The **bottom right quadrant** represents practices that are at risk, i.e., drivers of overall satisfaction that rated below the weighted average of satisfaction. Items in this quadrant should be **given priority**.
- The **upper right quadrant** represents practices that are strengths, i.e., practices that are also drivers of overall satisfaction and rated higher than the weighted average. The items in this quadrant can serve as examples and should be **capitalized on**.
- The **upper left quadrant** represents practices that have a low correlation to overall satisfaction but have higher rates of meeting needs than the weighted average of overall satisfaction. The items in this quadrant are not priorities, but should be **maintained**.
- The **lower left quadrant** represents practices concerning issues of secondary importance, i.e., items that scored below the weighted average for overall satisfaction but were found to be of low importance. These are areas for improvement and are practices that might be useful in some cases, but would be of little or no value in an "ideal" model of the practice.

The index of importance of a practice consists of its correlation to overall satisfaction. It is important to understand that this measure is relative. Since all items are relatively important in the eyes of respondents, the horizontal axis (index of importance) only serves to divide the indicators into two categories (left half and right half of the horizontal axis), in order to prioritize certain courses of action.

Results

The rate of response to the needs of families in the 12 targeted practices, cross-referenced with the index of importance placed on them, enables us to identify:

A. Practices to prioritize

B. Practices to capitalize on

C. Practices to maintain

D. Practices to improve

A. Practices to prioritize

The **lower right quadrant** in **Figure 4** shows items with higher importance and lower response to needs than the weighted average of these two. In this quadrant, the importance placed on the indicators is high. An improvement in the response to needs for these indicators would translate into an increase in overall satisfaction.

→ The dimensions that combine the components of the work of linking interventions and services and of advocacy and promoting the user's interests predominate in this quadrant.

→ As far as the **work of linking interventions and services** is concerned, two of the three practices included in this dimension should be prioritized. First, we find the *coordination of the various types of care and services received by the child*, followed by the *development and presentation of an individualized service plan that involves other practitioners and/or external partners*.

→ A similar scenario appears with regard to **advocacy and promoting the user's interests**, i. e. two of the three practices in this dimension: *helping with the various steps concerning the child* (e. g. visiting daycare centres, finding a summer camp, etc.) and *providing information on resources available in the neighbourhood*.

B. Practices to capitalize on

The **upper right quadrant** contains indicators that are above the weighted average in terms of importance and response to need. Again, the importance placed on the indicators is high. These are therefore practices that meet the needs of families and contribute greatly to their overall satisfaction.

→ The dimension of the **transfer of knowledge and parenting tools** is the most strongly represented here. Two of the three practices that make up this dimension relate to *supporting the parent, listening to them and supporting them in their experience*, as well as *showing them how to teach and work on things with the child* (e.g., facilitating communication, learning certain words or behaviours, etc.).

- → The third practice in each of the two dimensions found in the quadrant of items to prioritize (**linking interventions and services** and **advocacy and promoting the user's interests**) appears here because the rate of response to the needs of the families is higher than average. These items include *obtaining services* (e.g., respite, subsidies, adapted transportation, summer camps, etc.) as well as *linking with other practitioners and/or external partners involved with the child* (e.g., organizing meetings with the staff of the school or daycare the child attends).

C. Practices to maintain

The **upper left quadrant** contains practices that are lower in importance and higher in response to needs than the weighted average of these two. This includes items that do not necessarily require work to improve.

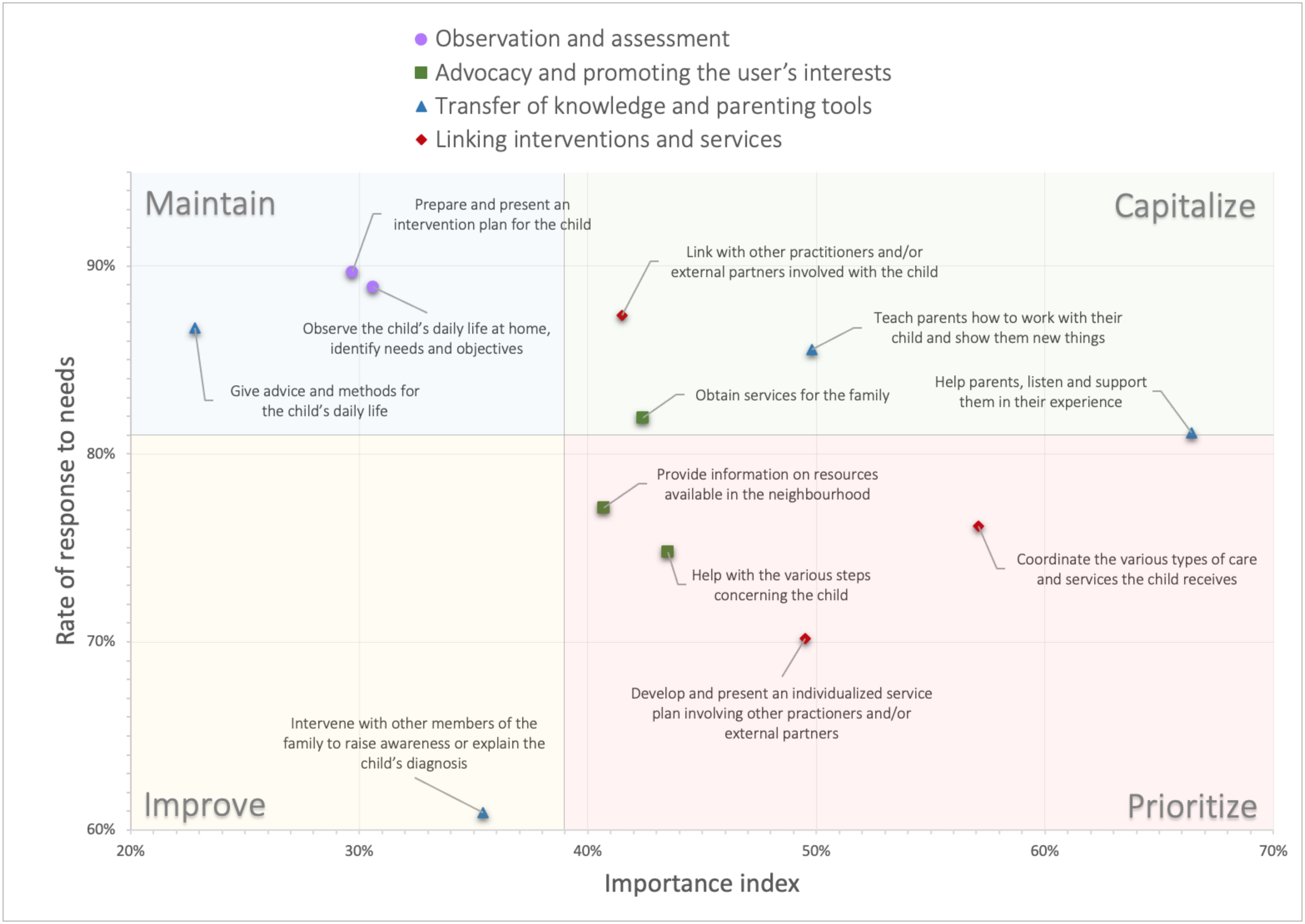
- → Although the importance placed on these practices is lower, all items in the **observation and assessment** dimension are found in this quadrant and achieve a higher rate of response to needs than all others, i.e., *observing the child's daily life and behaviours at home* and *developing an intervention plan for the child*.
- → The final item in the dimension of **transfer of knowledge and parenting tools**, considered less important but equally satisfying as those mentioned above, involves *giving advice and methods to assist in the child's daily life*.

D. Practices to improve

Lastly, the **bottom left quadrant** contains practices that are below the weighted average in importance and response to needs. Improving the response to needs for these items is preferable and would result in an increase in overall satisfaction, but less than for the practices to prioritize (A).

Only one practice is found in the quadrant of items to improve, which is *intervention with other family members to raise their awareness or explain the child's diagnosis* (**transfer of knowledge and parenting tools**).

Figure 4: Chart of prioritization of practices



Review of practices recognized in the literature

Recent literature supports many of the analyses, findings, and recommendations in this study. A targeted and analytical review of literature from a variety of sources indicates that relatively little research has been done on patient navigation in autism, despite all the existing research concluding that there are significant benefits to using and implementing patient navigation programs.

Barriers to access and to patient navigation

A body of research reports barriers to accessing services for families who have a child with ASD. Delays in accessing a diagnosis, along with wait times to access services, are a main barrier cited by parents (Todorow, Carlyn, James Connell, & Renee M. Turchi, 2018). In a model similar to patient navigation in autism, the "medical home," as well as the lack of community and clinical resources, is an issue raised by both professionals and parents (Todorow, Carlyn, James Connell and Renee M. Turchi, 2018). Structural and systemic conditions of service, as well as delivery of care, therefore play a critical role in the success of patient navigation (Thygesen et al., 2017), which cannot "navigate" on its own. This is an issue that was raised more than once during presentations of the analyses and co-construction of this study's findings and recommendations.

A Quebec study (Picard, 2012) directly echoes a key point in the parents' testimonies that we collected, namely the feeling that they lack access to the services offered and that these services are hidden from them. Even though Picard's study concerns parents of people living with an intellectual disability, it reveals a perceived barrier that is common to both these populations and the people around them.

On the practitioner side, two recent studies cite the lack of training for professionals in patient navigation as a potential barrier to fully developing this type of intervention. This limitation is raised both by practitioners themselves (Todorow, Carlyn, James Connell and Renee M. Turchi, 2018) and by the various stakeholders (Broder-Fingert et al., 2019). While this topic was less frequently discussed in interviews with the PNs in our survey, it is an issue that has emerged as a concern in the field, particularly for clinical supervisors and managers.

These barriers echo the findings in other fields, such as children's mental health services, where parents identify a lack of information and services as key challenges (Hansen, Anna Sofie, Gry Kjaersdam Telléus, Christina Mohr-Jensen and Marlene Briciet Lauritsen, 2021).

Echoing our point regarding the "professionalization" of parents, Singh (2016) notes that parents find themselves having to connect a medical understanding with a social understanding of autism. This type of parenting is often made easier by the parents' social and cultural capital, thereby pointing to the potential for unequal access based on the family's material and symbolic resources.

Tasks in patient navigation: the various models

Current models that identify and organize the various patient navigation tasks are often rooted in nursing. They are sometimes less transferable to other fields, but sometimes have interesting parallels. For example, in a 2017 Canadian study on patient navigation in oncology (Jeyathevan et al., 2017), the role of advocate and representative for patients emerged as central. This is consistent with our research, which proposes a quadrant of tasks associated with patient advocacy. However, this 2017 study and others (Beresford et al., 2020) involved intervention with adults, which significantly changes the intervention situation, as well as its focus. For example, in this type of model, there is an emphasis on empowering the patient (Jeyathevan et al., 2017) and promoting "self-management" (Beresford et al., 2020). Clearly, patient navigation takes on a different form for families who have a child with autism, and we have seen certain limitations of an approach that devolves all solutions and interventions to the family (Danilo Martucceli, 2004. "Figures de la domination," *Revue française de sociologie*, 45-3, 469-497).

Patient navigation practices in nursing otherwise involve similar tasks to those examined here, i.e., assessment, information, support and coordination of services (Saucier & Biron, 2018). The assessment role of patient navigation is the subject of further analysis in the nursing model, especially in Quebec (Fournier, Simard and Veillette, 2015). We can learn from this study that a good basic assessment of needs will subsequently improve the organization of care, which is confirmed in our results.

However, we did not find a model that conceptualizes and organizes tasks in a flexible way that can be used as a tool. Instead, the models are more like lists of tasks that belong to a specific field of health care.

Successful patient navigation and current best practices

Our analysis of representations of a "successful" patient navigation intervention for families and practitioners supports the best practices identified in recent literature.

Building the intervention plan around the parents' needs and the child's strengths, among others, is a practice found to be successful in a recent U.S. study (Pizur-Barnekow, Kris, Amy C. Lang and Brian Barger, 2020). Our research shows, in a similar way and going even further, that the family's needs and expectations must sometimes be translated into the terms of services offered by their PN, so that the definition of the situation is identical for all stakeholders.

Three major conditions for success that emerge from this study also appear prominently in recent literature: the importance of emotional support for parents, building a strong therapeutic alliance and a culturally sensitive approach.

Emotional support for parents, while emerging as an informal but central aspect of the practice studied here, is at the heart of multiple studies on family navigation in autism (Broder-Fingert et al., 2020) or in general (Camden et al., 2020). The importance of emotional support is also an element that stands out in nursing patient navigation practices with adults (Loiselle et al., 2020).

This support is best provided, of course, as part of a therapeutic alliance with parents that is based on mutual trust and free of judgment and guilt (Lewis et al., 2019; Goss et al., 2021). This winning condition for patient navigation is also strongly emphasized in this study. On the professional side, it involves overcoming barriers to parental involvement in the navigation process (Broder-Fingert et al., 2019). A recent pilot study suggests peer support, flexibility in appointment times and a culturally sensitive approach to maximize parental involvement (Ladarola et al., 2020). It is noteworthy that many participants in our study benefitted from services in a community setting that encourage social support among peers.

Professionals in patient navigation, on the other hand, identify a lack of time (Todorow et al., 2018) as a barrier to the full investment required in order to build a trusting relationship with families. This issue was raised by the PNs we interviewed.

Lastly, a cross-cultural or culturally sensitive intervention is broadly recommended in the studies we reviewed (Millau et al., 2018, 2019; Broder-Fingert et al., 2020; Rivard et al., 2020), confirming a finding that emerged from our data. It is important to remember that this type of intervention, although designed to work with individuals or families who are not part of the dominant national culture, can also be applied to interventions with Canadian-born families, and therefore aims to address and take into account the differences in norms, representations and ways of doing things.

Documented effects of patient navigation

Regarding the effects of patient navigation, various studies have noted an improvement in continuity of care in the field of oncology (Pautasso et al., 2017). As for patient navigation, the main positive effect is better and faster access to a diagnosis (DiGuiseppi et al., 2020; Feinberg et al., 2021). Improved access to services for immigrant families is also an effect documented in several recent studies (Millau et al., 2019, Rivard et al., 2019; Feinberg et al., 2021). This is consistent with further research on the differential effects of patient navigation practices based on the characteristics of populations. Another field that has been well-documented for the beneficial effects of patient navigation involves practices aimed at transitions, particularly school transitions (Chatenoud et al., 2019; Fontil et al., 2020; Morton et al., 2021).

An analysis of recent literature on patient navigation, even if it more often concerns nursing practices, confirms and reinforces this study, both in terms of the barriers perceived by the stakeholders, as well as the best practices adopted and the conditions for success. The absence of an ideal model of patient navigation in the research, which to our knowledge offers only lists of tasks for patient navigation with families who have an autistic child, points to the importance of analytical and flexible tools for questioning and structuring the practice, such as those proposed in this study.

Issues and recommendations

Multiple sources of tension underlie the reality of patient navigation, as well as this report. After presenting the results of this study to various stakeholders (officials from the MSSS, practitioners, managers, families, researchers and interested public), in collaboration with the research team, we have brought to light a number of issues that will help fuel our future research and discussion. These are continuums on which we can put the various situations based on organization of the services and work, as well as the concrete reality of families. These issues will also help us frame our further reflection on the topic.

The rights and needs of the child versus those of adults and the family

The question of who is the primary user and recipient of patient navigation arises especially in the case of children (here 0-7 years) and their families. As the family is responsible for the child's well-being, it is also the first judge of the child's needs. On the other hand, their interdependence ties the well-being of each family member to that of the others. However, it is important to remember that this tension may be heightened in the case of interventions with teenagers, for example.

Direct services versus coordinated services

Although patient navigation is intended to offer more of a coordination and linkage of services, we cannot rule out the fact that this type of practice may involve direct intervention. According to the various models, the two poles of this spectrum are calibrated to each other. Conversely, patient navigation cannot take place in a vacuum of services, since its purpose is, among other things, to coordinate existing approaches and interventions.

Arriving before diagnosis versus arriving after diagnosis

The question of arriving at the right time vis-à-vis the diagnosis is a concern among the various stakeholders interviewed, as well as the research audiences. While some lament the fact that patient navigation currently happens too late and is not deployed immediately after diagnosis, others mention the idea of arriving before diagnosis, especially with the aim of making this decisive and often difficult moment easier for families and encouraging relational continuity.

Relational continuity versus one-time episodes

With regard to isolated episodes, the desire to provide relational continuity between practitioners and the families they work with is at odds with the way the RSSS currently provides services.

Overspecialization of the "navigator" role versus inclusion in various roles

The navigator's role and way of doing things, which appear to produce their share of convincing evidence, may be destined to become more widespread. A question that often arises is whether to make this knowledge and these methods available to various positions and professions in the RSSS, or whether to overspecialize the navigator role. This question provides fertile ground for further studies rooted in clinical and daily realities.

Social work versus psychoeducation

The academic discipline to emphasize in choosing practitioners and reflecting on the creation of positions is an issue that has been raised multiple times. Since patient navigation involves tasks and expertise that are specific to both fields, practitioners are sometimes required to perform tasks that belong to a field not their own. Faced with this issue, some practitioners prefer to work in pairs.

Key takeaways and recommendations

We are making all these recommendations in a context where the well-being of families depends on receiving significantly more services (including IBI, occupational therapy, habilitation/rehabilitation and nutrition, if applicable) with a significantly shorter delay, especially given the importance of early intervention for this type of diagnosis. A succession of reforms to the network, in addition to the impact of COVID-19, lockdowns and rounds of offloading, have created an unprecedented crisis whose very real damage we see daily on the ground.

As such, according to the stakeholders consulted and the analysis of various data, the ID-ASD-GDD pilot project in Montreal enables us to put forward certain proposals:

Concrete practices that influence the satisfaction of families

Support for parents, a common PN task but sometimes referred to as informal by practitioners, is the practice that best responds to parents' needs. Parenting tools, such as teaching to teach, is another practice that emerged as important to parents, and most responsive to their needs in the study. These can be thought of as more direct early interventions that have the potential to rapidly change families' daily lives, and are therefore especially valued in a patient navigation intervention. This set of practices should continue to be promoted.

Linking services and advocacy are the two groups of practices that parents identified as important, but these needs are not as well satisfied at this time. Developing an ISP and coordinating services emerged as two practices to be improved, as did assistance with the process and information about available resources. These are important tasks of patient navigation, but much less transferable to parents, in the sense that they are also more specialized tasks, involving more niche information, as well as the power to act that comes with the title and status of patient navigator. Improving these practices would also increase families' satisfaction with patient navigation.

Observation and assessment are a dimension that are considered less important, but which parents feel satisfied with. We could argue that this is perhaps a more invisible step for them, and that it is more the results of this observation/assessment (e.g., finding the right resources based on this observation) that pay off for them, which explains the lower score.

Only one practice qualifies as both less important and less satisfying: intervention with other family members. This may be due to various reasons, such as a less pressing need compared to other needs, or the fact that patient navigation has an impact on the whole family even when there is no direct work with other family members. In any case, it is a practice that could also increase overall satisfaction, but to a lesser extent.

With respect to patient navigation in general, as practiced in the project, the following proposals have emerged:

Trajectory and delivery of services:

- ⇒ Arrive at the right time vis-à-vis the diagnosis.
- ⇒ Better calibrate the caseloads of practitioners.
- ⇒ Stay involved in families' lives for the long term and encourage relational continuity.
- ⇒ Expand the patient navigator role to various practitioners, **or** create specialized positions dedicated to this role.

Professional training and orientation:

- ⇒ Encourage the recruitment of candidates with strong personal qualities (interpersonal skills, compassion, interest in users, etc.).
- ⇒ Create patient navigator teams in pairs (social work and psycho-education), **or** have one person willing to play both roles.

Philosophy of intervention:

- ⇒ Build the patient navigator practice based on strong alliances with parents, making room for a division and recognition of each other's expertise (professional and experiential).
- ⇒ Give priority to a philosophy of intervention that puts therapeutic realism at its core (pragmatism, agreement between needs and means, focussing on the chances of success, etc.).
- ⇒ Raise awareness and provide training in intercultural intervention, including variations in social norms concerning child development, parenting, couples and families.

Future research:

- ⇒ Gain a better understanding of the immigration profile of families in the RSSS, how they differ from other families, and the differential effects of patient navigation on families' circumstances, if applicable.

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