REPORT SUMMARY

PATIENT NAVIGATION WITH CHILDREN WITH ASD AND THEIR FAMILIES:

Evaluation of a Montreal Pilot Project

RESEARCH TEAM:

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BACKGROUND

In order to obtain services in Québec's health and social services network (RSSS), children with an autism spectrum disorder (ASD) and their families have to face long waiting lists (sometimes the wait can be years long), knock on many doors (pediatrician, psychologist, CIUSSS, CRDI), contact different government ministries (health, education, transportation, families) and coordinate the various services for which they are eligible, as necessary. Patient navigation thus appears as a promising practice for facilitating formalities and procedures for families as well as their access to care and services and the coordination thereof.

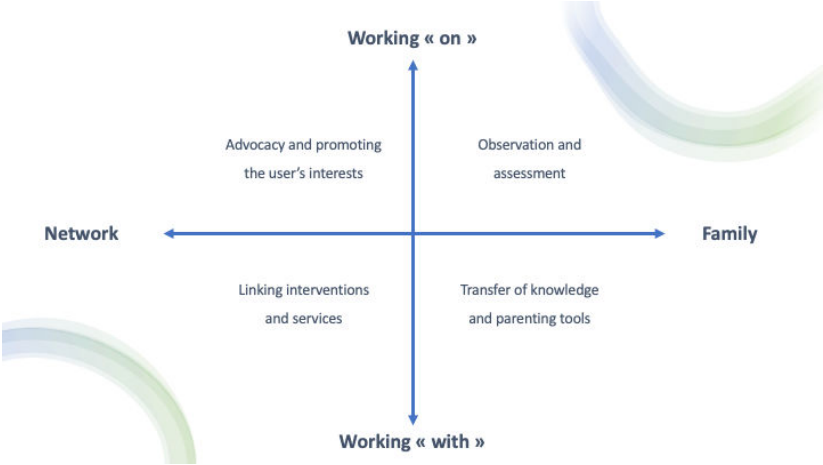
Patient navigation is a practice that became formalized in the 90s, born of a desire to counter social inequalities with respect to an often labyrinthine health care system that does not provide all citizens the same possibilities. The practice then extended to other types of care and services, including those related to ASD.

Through interviews with families and patient navigators, observations of the practice, analysis of administrative data, and the findings of a survey conducted among affected parents, we were able to identify the concrete practices that constitute patient navigation in autism within the framework of a pilot project conducted in five Montreal-area CIUSSS. Turning next to the needs and expectations of families, we inquired as to whether these practices are satisfactory to them and adapted to their realities.

FINDINGS

1. The concrete practices of patient navigation: an emerging model

Twelve concrete practices emerged from the analysis of the interviews and the observations. These 12 practices are grouped around two intersecting axes: one designating the beneficiary of the intervention (the RSSS or the family), the other qualifying the perspective of the intervention (working "on," from a position of exteriority and expertise, or working "with," from a standpoint of collaboration and co-construction). Accordingly, the 12 practices are distributed across four quadrants (or fields of action).



2. The satisfying of family needs

Providing support to parents, an ongoing yet informal task of patient navigation, is the practice that best meets the needs of parents. Parenting tools, and notably, teaching to teach, is another practice that the survey reveals as being important for parents and best meeting their needs. These can be thought of as initial, more direct interventions that can rapidly change the daily lives of families and that are therefore particularly appreciated within the framework of patient navigation.

Linking interventions and services and advocacy constitute the two groups of practices that parents consider to be important, but that represent needs not being met as well right now. The development of a personalized services plan (PSP) and the coordination of services stand out as two practices in need of improvement, just as are assistance with procedures and formalities and information on available resources. Though these are important tasks of patient navigation, they are much less transferable to parents, insofar as they are more specialized tasks, involving less-accessible knowledge and where the power to take action stems from the navigator's title and status.

Observation and assessment constitute an aspect deemed not as important, but with which parents express satisfaction. It could be argued that they perhaps constitute a less visible phase for parents, hence the lower score attributed to them. Only one practice qualifies as both less important and less satisfactory, namely intervention involving other members of the family. Different hypotheses may be put forward to explain this, but in all cases, the families that did benefit from it told us of their great satisfaction with it.

RECOMMENDATIONS

Trajectory and provision

- Arrive in a timely manner with respect to the diagnosis
- Better calibrate navigators' case loads
- Stay in the lives of families for the long term and favour relational continuity
- Generalize the navigation function, extending it to different workers or creating specialized positions dedicated to it

Intervention philosophy

- Build the navigation practice around a solid partnership with the parents, one that distinguishes and acknowledges the respective areas of expertise (professional and experiential)
- Foster an intervention philosophy with therapeutic realism at its core (pragmatism, a fit between needs and means, an emphasis on the probability of successful outcomes, and so on)
- Raise awareness of, and provide training on, intercultural intervention, including the variability of social norms surrounding child development, parenting, the couple and the family

Training and orientation of the position

- Favour the recruitment of candidates presenting a richness of personal qualities (interpersonal skills, compassion, interest in the users, and so on)
- Create navigation teams in pairs (social work and psychoeducation) or a single person ready to take on both roles

For subsequent research

- Develop a better understanding of the migratory profiles of the families in the RSSS, how they differ from other families, and the differentiated effects, if any, of patient navigation as a function of family situation.

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