

**Centre intégré
universitaire de santé
et de services sociaux
du Centre-Ouest-
de-l'Île-de-Montréal**

Québec 

**MIRIAM HOMES
USERS'
COMMITTEE
Annual report
2020-2021**

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2. MOT DE LA PRÉSIDENTE

As the president of the Miriam Home and Services Users' Committee of the CIUSSS West-Central Montreal, I am pleased to present our annual report of activities for 2020-2021.

The year 2020-2021 has been far from a thrilling "rollercoaster" experience; we've been on a fast and furious ride this year that has thrown us for multiple loops and left us breathless. The usual challenges of regular day-to-day life and functioning, as we once knew it to be, was replaced by many anxieties provoking and fearful unknowns. Figuring it all out under these unprecedented circumstances and leading in uncharted territory has been an incredible feat, and so, I must give kudos to our Miriam home directorate and staff for their tireless work and organizational orchestration of all the details that encompass provision of services to our clients while ensuring their health and safety.

The Miriam Users' Committee (UC) continues to appeal for the recruitment of new members to join our workforce. Two of our members had to take a backseat role and one resigned altogether. We are looking to hire a resource person to spearhead our upcoming prioritized initiatives and to ease the workload on our users' committee members. Although this has been a tough year, it was also a year of engagement, characterized by the sustained efforts of our Committee members to fulfil their mandated obligations representing users. To this effect, our UC members have contributed above and beyond their volunteer duties.

Regrettably, evaluating User satisfaction with the services received was challenged by administrative roadblocks and legal red tape regarding the policies and procedures required to contact and survey our clients. Strict measures in insuring client confidentiality were always followed in this regard and was never an issue in past years. As a result of such, the committee was forced to postpone our assessment projects to the early part of 2021.

Our UC, supported by the CUCI and our administrators, worked relentlessly with our community partners in petitioning the government to vaccinate our vulnerable patient population. The roll out allotment of vaccines and the criteria for vaccination that was based on age was the major defining factor that trumped this patient population's need to be considered as a target priority group. We didn't hesitate to go public when, unfortunately, some of our clients living in our group homes and the staff who cared for them, began falling sick. Although somewhat late, we finally succeeded in our persuasiveness. Our users view this to be the government's failure in management of COVID as it pertains to meeting the needs of people with Intellectual disabilities and Autism.

Our Miriam administrators have met with our Users' Committee on a frequent and regular basis so that we could work collaboratively in our efforts to serve our clients. The lines of communication have been flowing and we have been dealing with any issues that arise in a timely and efficient manner.

The Miriam Home Users' Committee has been playing a key role in the health and social services system. We have acted in conjunction with other bodies, as guardians of the rights, dignity and best interests of MH users. In this regard, we have fulfilled our role in remaining vigilant and responsive by petitioning the Ministry to revise the *Intensive Care Unit Triage Protocol* in Quebec, as we identified legal and ethical dilemmas in its original format. Our efforts to effectuate the changes to the protocol should more adequately protect our client's lives and well-being if they unfortunately have to access an intensive care unit in the context of the pandemic. In addition, we have organized to proactively guide hospital policy on the provision of an accompaniment to our clients that require an advocate or sitter at their bedside at all times, this in order to ensure their safety and security during a hospitalization. We have also positioned ourselves at the forefront in supporting our community advocacy organizations with political activism aimed at collective common goals. This year, we petitioned the government to raise the personal spending allocation sums for clients living in RIs.

We network with our partners in care to have our concerns heard, respected and considered in regards to any planning or transformation of services, and we insist on actively participating in our institutions working committees and Kaizen sessions, which we feel serves as a solid foundation of communication and transparency in the relationship we have with our leadership.

Onward into the next year, we remain steadfast in our commitment to serving our Miriam Home Users and look forward to the rainbow of hope and prayer that "*Ça va bien aller*" "All will be Ok".

Debbie Schichtman, President of Miriam Home and Services Users' Committee

3. PRIORITÉS ET RÉALISATIONS DE L'ANNÉE 2020-2021

ACHIEVEMENTS

- Opened lines of communication with new CIUSSS rehabilitation directorate;
- Planned ongoing communication strategies to facilitate outreach to our users. We are proud of our independent website and social media platforms – through which we are able to communicate with our users/families and concerned citizens pertaining to all matters of interest and concern – to inform them of their rights and obligations, and to provide relevant and supportive links to community organizations and resources;
- Continued request for UC representation on all MH committees;
- Scheduled biweekly/monthly meetings with the Miriam Home Directorate to discuss COVID-related issues and client concerns;
- Increased presence within social media platforms via regular posts of educational articles and resources;

- Launched outreach campaign to increase visibility of the UC to MH users and their families via a serial postcard mail out;
- Collaborated with the MH Directorate to offer an on-line information session on MH Services (registration of 100 participants);
- Held AGA virtually (35 participants);
- Worked in collaboration with the CIUSSS Users' Committee on the implementation of governmental centralized, harmonized, safe and confidential e-mail communication;
- Requested presentation from complaints commissioner at UC meeting;
- Expressed concerns regarding the 2019 relocation announcement of the programs and services currently taking place at the Lori Black Community Centre (LBCC) as a result of the sale of the property. Throughout the last fiscal year, we have continued to inquire with the MH Directorate on the sale of the LBCC property, and consulted on the relocation of programs and services;
- Advocated for revision to COVID Triage protocol;
- Advocated for prioritization of COVID vaccination for our vulnerable clientele;
- Advocated for established protocol and funding for hospital accompaniment for MH clients;
- Advocated for creation of, and stakeholder participation in, a committee for special needs clients at the JGH;
- Advocated for the establishment of an adapted medical/dental clinic for our clientele at Rene-Cassin site;
- Consulted with Directorate on the sale of land adjacent to the Guimont Complex;
- Liaised on the creation of a choir for MH clients (project to commence once COVID restrictions ease up);
- Commenced collaboration on research project "The user experiences and agency among adults with IDD" (project delayed to Spring 2021), with Dr. Tara Flanagan (McGill University). There are two UC representatives included in the research and one member of our committee will participate in a focus group;
- Formed a sub-committee to conduct a MH user satisfaction survey;
- In collaboration with the CUCI, supported the funding of a Quebec-based documentary, following adults with special needs during COVID entitled *Just as I Am* <http://shiramovie.com/teaser/> ;
- Advocated for quality control and client safety in residential services, so as to minimize the risk of neglect and maltreatment of users.

PRIORITIES

- To hire a resource person in order to optimize the manpower and mobility of the UC;
- To recruit two committee members to represent all Colleges of the MH;

- To advocate for a transparent complaints procedure, in which the UC plays an active role, to ensure the rights and anonymity of users and their caregivers are respected;
- To launch a MH user satisfaction survey;
- To advocate for rigorous due diligence in home manager/staffing recruitment policies and job qualification requirements;
- To provide real time pandemic healthcare related issue updates to inform our clients and their families of changes in ministerial decrees and to give useful links to follow;
- To promote webinar sessions of public interest topics;
- To continually increase our computer/technology competencies to facilitate outreach;
- **To advocate for needed changes aimed at enhancing and safeguarding the user experience.**

4. COMPOSITION ET PORTRAIT DES MEMBRES

	Collèges électoraux / Electoral Colleges	Élu(e)s par acclamation	Type de membre		Rôle
			Usager (famille)	Usager	
1	Ressources accompagnement continue (RAC)	Debbie Schichtman	X		Présidente
2	Services de réadaptation 0-6 ans	Vacant	X		Vacant
3	Services de réadaptation 7-21 ans	Carrie Markin	X		Secrétaire
4	Services de réadaptation 22 ans et plus	Helene Donath	X		Membre
5	Programme de jour pour adultes au Centre communautaire Lori Black	Electra Dalamagas	X		Vice- Présidente (on leave)
6	Programme de jour pour adultes – autre sites	Toby Benlolo	X		Trésorière, Représentante au CUCI
7	Services résidentiels RI-RTF	Rosanne Superstein	X		Membre (on leave)
8	Appartements supervisés	Andrea Leibovitch		X	Membre

	Collèges électoraux / Electoral Colleges	Élu(e)s par acclamation	Usager (famille)	Usager	Rôle
9	Enclaves, programmes pré-emploi et soutien à l'emploi	Judy Zimlichman (démission Nov 2020)	X		Vacant
10	Usagers résidant avec leur famille naturelle	Jeff Wagen	X		Membre

5. COORDONNÉES DES MEMBRES

The representatives of the Miriam Home and Services Users' Committee can be contacted at the following:

Email : userscommittee.miriam@ssss.gouv.qc.ca

Telephone: 514-345-0210 poste 236

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6. BILAN DES ACTIVITÉS Du COMITÉ DES USAGERS

1. Renseigner les usagers sur leurs droits et leurs obligations

- **Virtual Informational Webinar (December 3, 2020)**

- We hosted our first webinar entitled *We are your users' committee – We are your voice*. Our directorate and senior managers presented on Miriam Home and its seven service offers:

1. Access, evaluation and orientation (AEO)
2. Adaptation and rehabilitation for the individual (children and adult services)
3. Support and consultation to families and loved ones
4. Specialized support and consultation to partners
5. Community integration
6. Work integration
7. Residential and respite

- This 60-minutes overview of MH services was followed by a 30 minutes question and answer period. The limited restriction on the Q&A period left many unanswered questions. There were 100 registrants, 75 of which opted to be added to our contact list. This webinar was uploaded on to our media sites:

<https://centremiriam.com/en/2021/01/12/services-offered-by-miriam-home/>

The event was a testament to our tenacity in transforming our outreach modalities to conform to COVID life realities. Most of us lacked the technical skills related to the Zoom

and Teams platforms let alone the ins and outs of webinar hosting; the organizational aspect of this initiative was overwhelming. We had an exceptional evening.

- **Outreach campaign**
 - Hired a consultant to create an outreach campaign
 - A serial postcard mailout to all about 800 users
- **Increased presence on social media** (Facebook, website), informing and sharing pertinent information relevant to the clientele. On Facebook, we currently have 159 followers.
- **All board meeting are open to the public.** Notice of meetings is given on our Facebook page.
- **Miriam Home Users' Committee Virtual Annual General Meeting** (December 17, 2020) with guest speaker Carly Goodman: "An Inclusion Pirouette in a Pandemic: Hope, Discovery and Forging Ahead" highlighted our Users' rights to remain active in community integration and socialization programs. We informed our Users of our:
 - Committee mandate
 - Annual plan and budget
 - Special projects
 - Users' Rights
 - How to file a complaint

2. (a) Promouvoir l'amélioration de la qualité des conditions de vie des usagers.

- Proactively guided hospital policy on the provision of an accompaniment to our clients that require an advocate or sitter at their bedside at all times, this in order to ensure their safety and security during a hospitalization.
- Invited the Service Quality and Complaints Commissioner to present policies on neglect and mistreatment of clients.
- COVID crisis – advocated for revision of the *Intensive Care Unit Triage Protocol*, vaccination prioritization, client safety and continuation/access to services.
- Streamed live musical concerts on our Facebook platform, to improve the moral and socio-emotional well-being of our users. We thank Rachel Dara for her talented musical contributions.

2. (b) Évaluer le degré de satisfaction des usagers à l'égard des services obtenus.

- There was a significant delay in commencing the survey, with respect to contacting and obtaining informed consent from MH users. With the assistance of CUCI, the budget was approved to complete the survey in 2021.
- Restrictions imposed by the CIUSSS legal team delayed the release of client contact information to the external survey company. This was outside the control of the UC.

3. Défendre les droits et les intérêts collectifs ou individuels des usagers.

Met with our Service Quality and Complaints Commissioner, Ms. Maude Laliberté, who presented an overview of all 2020 year complaints and Ms. Chantal Bellerose, Associate to the Quality directorate, Responsible for Quality, Risk Management, Accreditation, User Experience and *Planetree* in order to address a detailed list of questions related to 2 sentinel events that occurred this year. We are awaiting official reporting back to us after the investigations have been concluded.

4. Accompagner et assister, sur demande, un usager dans toute démarche qu'il entreprend y compris lorsqu'il désire porter une plainte.

The Users' Committee identified and raised concerns related to oversight in management practices in two intermediate resources (RI) settings. The challenges of ensuring proper check and balances in our residential models gives rise to the need for rigorous due diligence in home manager/staffing recruitment policies and job qualification requirements. Procedures for regular scrutiny and documentation will promote accountability and protect our client's psychosocial and physical well-being and overall quality of life.

7. TENUE DES RENCONTRES

a) Meetings of the Committee in 2020-2021: 7

August 27, September 24, October 22, November 19, January 18, February 11, March 11

*Note: Between April 1 and August 27, several adhoc meetings were held to address committee matters, COVID-related issues and the outreach campaign

b) Annual general assembly

On Dec 17, the AGA was held via Zoom, with 35 registrants. A recording of the AGA is available through links on our Facebook page and website.

c) Other meetings

- Committee meetings (bi-weekly or monthly, total of 11) with Miriam Home Directorate to address COVID-related issues and client concerns
- Subcommittee for media development
- Subcommittee for outreach campaign
- Subcommittee on users inquiries
- CUCI monthly meetings
- CUCI special project meetings
- Due to the COVID crisis situation, the MH-UC and the CUCI communicated regularly, either by text, email or virtually, to keep abreast of all of the changes

8. COLLABORATION AVEC LES AUTRES ACTEURS DU RÉGIME D'EXAMEN DES PLAINTES

- Maude Laliberté, Commissioner of complaints and quality of services, attended our committee meeting to provide an overview of the complaints process and address our questions (January 18).
- Met with legal counsel of CIUSSS in regards to sentinel event inquiries. Replies to our requests are pending legal investigation closure.
- Renewed membership with local advocacy organization

9. RÉALISATIONS ET PROJETS PRÉVUS POUR 2021-2022

- To fulfill our mandate to survey all our clients on their level of satisfaction with Miriam Home services. We are working with the Quality Directorate to quantitatively measure user's satisfaction and will be conducting a qualitative users satisfaction survey with Medaillon Groupe Conseils.
- To advocate for the improvement of checks and balances and quality control for residential services, so as to minimize the risk of neglect and mistreatment of users;
- To continue to provide real time pandemic healthcare related issue updates to inform our clients and their families of changes in governmental decrees and to give useful links to follow;
- To attend, promote or offer conferences (virtual or in-person);
- To continue with our user outreach campaign;
- To hold information sessions for users;
- To continue diffusing relevant information via our social media platforms;
- To increase and strengthen communication channels with directorate;
- To maintain UC involvement in the Miriam Home/LBCC relocation committee;
- To create a subcommittee to establish the criteria to hire a resource person to support committee efficiency;
- To explore the opportunity to liaise with Best Buddies (www.bestbuddies.ca) and adapt this program for MH users;
- To advocate for ISP reviews/revisions to be communicated to users and families on a yearly basis;
- To develop patient care prioritized on needs without other discriminatory factors;
- To assist and support users who wish to file a complaint or make their dissatisfaction known.

10.CONCLUSION (ENJEUX ET RECOMMANDATIONS)

The following are our Users' Committee recommendations:

REHABILITATION DIRECTORATE

1. We recommend that the directorate assume more responsibility for clients in residential services.
 - a. MH must ensure that proper checks and balances are in place to ensure the physical safety, integrity and dignity of clients.
 - b. Ensure proper checks and balances in our residential models for rigorous due diligence in home manager/staffing recruitment policies and job qualification requirements; and to develop procedures for regular scrutiny and documentation to promote accountability and protect our clients' psychosocial and physical well-being and overall quality of life.
 - c. Encourage the MH to enforce and promote the policies to combat neglect and abuse:
 - Support people in their efforts to prevent abuse;
 - Ensure understanding and respect of the Act on mistreatment;
 - Carry out audits and adopt recommendations for corrective measures.
2. Encourage MH to adopt policies that enhance client well-being and promote social inclusion and community integration.
3. Ensure that a Users' committee representative be part of any working committees pertaining to planning, implementation and review of services.
4. Miriam Home must seek family involvement and respect family wishes in regards to evaluations, reports, protocols or modification to services.
5. Miriam Home should not outsource services for 'high needs' individuals with autism and intellectual disabilities to community sector organizations who do not have the means nor expertise to deal with such high needs clientele.
6. We recommend that Miriam Home and Services:
 - a. Optimize services to our clients by using resources within our CIUSSS;
 - b. Adhere to client-centered practices as opposed to establishment-centered practices;
 - c. Remember that all clients with disabilities deserve, and benefit from, rehabilitation services;
 - d. Recognize that individuals with higher needs will require more services.
7. Miriam Home should not attempt to apply 'medical model' of service (or services episodes) to social services/rehabilitation services for autism and intellectual disabilities. The model should be aimed for a continuum of services over the lifespan of a client versus episodes of services.
8. MH administration must promote and improve communication with users/families and its users' committee representatives.