Les expériences d'exclusion et d'inclusion sociales chez les personnes vieillissant en situation de neurodiversité et leurs proches The experiences of social exclusion and inclusion among people aging with neurodiversity and their families



The Story of Monsieur X

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Monsieur X's Portrait

Monsieur X (M. X) was born in 1955. He is intelligent, quick-witted, and friendly. He enjoys engaging in conversations with people wherever he goes. He likes to joke, tell jokes, and has a dry sense of humor. M. X comes from a close-knit family and is the eldest of three children. He has two younger sisters with whom he remains close. M. X described his family as loving. He also shared that his father was old-school and strict. His father's role was to take care of the family financially, while his mother stayed at home with the children. He stated, "My dad wasn't often at home". M. X remembers the division of tasks between his parents based on gender, saying, "Because my dad didn't do many household chores in my time". M. X stated that he grew up in a strict environment, and if he or his sisters misbehaved, there were consequences. He expressed, "It wasn't easy. That's why it made me rebellious. I withdrew, I don't know if you understand what I mean... To open up, it took me a long time". When comparing his childhood to that of children today, he jokingly said, "I couldn't be whiny. Nowadays, kids talk back to their parents outright... I feel like if I had talked back to my parents, I wouldn't be in this world anymore".

M. X exclaimed that he learned to be a "macho man" from his father, saying, "So I used to say that household chores were for women... I kept that mentality [laughs]". His mother would often tease him about it, calling him her "macho". The nickname stuck, and M. X now uses it to describe himself. "That's right. Excuse me for the expression, but I am a bit of a "macho"". With a slight smile on his face, he shared with us, "My mother also used to call me "damn macho"... I didn't like it... no, because I would come up with "macho" quotes, and she would say "damn macho". I didn't like it when she called me "damn macho". She should have said "sympathetic macho", "generous macho", or "wonderful macho", but not "damn macho". For me, that was sacrilegious, blasphemous for my mother to curse her own son".

M. X doesn't like to use labels to define himself. He told us that he attended a "special school" when he was young and was proud to mention that he excelled in mathematics: "I was good at math except for division, but the rest was very good, multiplication, subtraction, and addition were all very good. I can do calculations like if you write down numbers, let's say 70-44, I can do it, no need for a calculator... I can do it...". Unfortunately, M. X has been a victim of numerous intimidations and has experienced difficult times because of it. He told us about the time when someone broke his arm, and he ended up in the hospital, "All kinds of problems, things like that. I've had my arm broken by someone, by, what do you call it... he pushed me down the stairs, he wasn't mad at me, but he was angry, and let's say I was the first one, I was in the wrong place at the wrong time". To this day, M. X despises bullies and stands against those who, in his opinion, treat him or others disrespectfully. Respect is the most important value for him: "That's right, there are people who, when you tell them things, they make fun of them: "Oh, he's this, he's that", "he does this, he does that", "he's crooked". Those are value judgments".

Due to his specific learning needs and challenges, M. X recounted that at the age of 16, he was placed in an institution. "Because I had issues... It was my parents who placed me there". M. X hated going there but resigned himself to it in order to gain his independence. "Yeah, I didn't accept it easily". M. X was determined to become independent, to live on his own, in his own place, and to control his own decisions and choices. Overall, he spent ten years in an institutional environment, staying at the hospital from Monday to Friday. For a while, he received visits from his parents, and he could only go out with them. Over time, he managed to gain the right to visit his parents alone

on weekends. "I had my weekends, for a while I had my weekends. I could go home every weekend". The ten years he spent in the hospital were a dark period in M. X's life, and he chose not to share too many details about his experiences. However, to this day, he remains marked by the things he saw during his stay at the hospital.

After experiencing bullying and disrespect throughout his life, M. X refuses to tolerate such behavior. He gave an example of a past relationship that had become toxic, leading him to end it in 2003. "I had someone, about twenty years ago. I cut him out of my life in 2003, okay. Yes, someone had to help me because I was going crazy with that guy". He then explained, "Yes, because I was losing control... I was hitting myself... and I became aggressive. It was, excuse the expression, a poisonous relationship... Because I was being deceived". He continued, "We got fooled, I mean. And how do you know? He was a guy who had certain issues, okay? But he didn't want to deal with his issues; instead of solving his problems, he tried to solve other people's problems. Do you know what we call that? A shoemaker with poorly mended shoes". The experience had a considerable negative impact on M. X's mental health and well-being: "Even then, even when he was out of my life, I would wake up at night".

In 1977, M. X tried living in a family-type resource for a short period, but it didn't work out, so he returned to the institution for a while. "Sometimes I arrived a little late [...] They scolded me a bit. Instead of coming back at 9:30, I came back later, around 11:00-11:30. Yes, that's why they reduced my hours after that". Eventually, at the age of 30, he moved and settled into a supervised apartment that suited him, where he stayed for 5 years, after which he went back to another hospital for some time. M. X enjoys staying up late, so it was great news when his support team found him an apartment above a pet grooming store and a restaurant that served delicious tomato sandwiches and fully loaded lasagnas. He was able to enjoy the freedom and independence he had always dreamed of: "You could do what you wanted... Eat whatever you wanted... eat at any time you wanted". M. X lived in this apartment for over 18 1/2 years, and during this time, he received regular visits from caregivers who checked in on him: "I was supervised, someone came to check on me every day".

M. X has many friends that he has met over the years through his involvement in various groups and organizations. Having genuine friendships is a central element of his life: "I have real friendships and fake friendships. Because when a person doesn't respect you, they are not your friend". He also enjoys taking walks in his neighborhood and has met numerous people during these strolls. He knows the public transportation system like the back of his hand. "I even took buses too... I liked taking metro rides. Many years ago, I used to take the metro from [name of Montreal subway station], and I would go to the end of the line, and then I would come back". He continued, "Sometimes I would go to a brewery when I was young, I would go out".

M. X fondly talked about a friend he made in the neighborhood where he used to live. They have remained good friends and help each other out from time to time. He recounted a recent experience when he went with her to buy a kitten. "The love of the people I know. I have a friend who used to live nearby, and she worked not far from where I used to live. I still visit her sometimes, and last week I went... with her, to get a kitten she wanted". He explained, "She wanted to get a little cat, and she wasn't used to driving in that area, so she wanted me to accompany her, and I did". M. X stated that he enjoyed being with his friend and taking care of the kitten on the way back. "When we were in the car, I petted and cuddled it... It's like it's my cat, but it's not my cat, but I don't know

if you understand what I mean". This memory reminded him of a bird he had as a child. With his characteristic deadpan sense of humor, he recounted, "And when we bought it [a bird], it was guaranteed for 30 days at the pet shop. Once, we exchanged one because it didn't sing".

M. X doesn't like to talk much about what aging means to him, except to say that: "Old age scares me". He mentioned that uncertainty worries him because of "Not knowing what's going to happen... illnesses, the whole kit". In recent years, M. X has had to deal with health issues. He also had to face an unexpected move from his beloved apartment to an intermediate resource (IR) in 2021. When his long-time caregiver announced their retirement, his caregiver and sisters decided it was time for him to move to an IR where he could receive more support. M. X was upset about this move. "One of the caregivers who took care of me, she retired, and then... that [the move] put me in a difficult situation... when I found out, I cried so hard". Although he has tried to adapt and met new people, he doesn't like the idea of having to face restrictions on his outings or his diet again, as was the case in his previous life.

M. X spoke with sadness about the aging of his parents and their passing. He shared that his mother passed away in 2009, and his father passed away in 2011. He remembered when his father lost his driver's license for medical reasons. He said, "...dad had a stroke, and he recovered, but... he had a special pill, you know?". This event was significant and made him realize his father's fragile health. It was only two years after that his father passed away. The deaths of his parents within a few years of each other were very hard for M. X. He described this period as, "Difficult... very difficult... The time is difficult because I no longer have my parents, my parents have passed away". He shared that he misses his parents and wishes he "would have gone before my parents". However, he knows he can still rely on the constant support of his two younger sisters and his brother-in-law.

The happiness that Monsieur X feels when he takes a walk in his neighborhood, his sense of humour that always makes people laugh, his friendly nature, and his kindness have helped him establish meaningful connections throughout his life. With his strong character, he expresses and defends his principles and human values, including respect and self-determination. Despite the recent difficulties he has encountered as he grows older, Monsieur X remains determined, proud, and independent. He benefits from the support of many people in his social network, including caregivers from the community organization where he is active, as well as his friends and family.

Postscript - In memory of Monsieur X

This story celebrates the life of Monsieur X who sadly passed away in the winter of 2025 after having experienced multiple transitions in his housing, since we completed our interviews with him. He also faced many service gaps and experiences of system related challenges that further compromised his health and well-being. Monsieur X was proud to be a part of our research project. We were privileged to include him as a research participant, and we are deeply honoured to have had the opportunity to get to know him and to share his story with you. Rest in peace, Monsieur X.

Intersectional Life Line of Monsieur X:

