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



Tina's Story

June 30, 2022







Tina's portrait

Tina is a 61-year-old woman who currently lives in a group home (family type resource) in a supported housing community not far from Montreal. Her group home is one of several in the supported housing community that has access to many activities and programs and is close to nature. Tina moved to her current group home in her late 40s after many years of struggle and uncertainty with both her own health and her housing situation, which she attributes to decades of alcohol use. "When I came here after I was hospitalized. I was hospitalized, that's why I came here. Because of alcohol, alcohol. Too much... and my liver was damaged. I had an intravenous in my arm. I had to walk, and I couldn't smoke and nothing... and really badly".

Tina openly shared her life story with us, beginning when she was in her early 20s. She began her story here because of the many important events that happened to her during this time in her life, both good and bad. Tina began drinking when she was around 21 years old. She told us "[I started drinking] when I was maybe 21. Yeah, going on 22. I started with a bunch of people. No, just not friends, just a bunch of enemies. Yeah, they were with my friend, I think I started drinking with them. Yeah... too bad". Tina's alcohol use and the impact this has had on her life and relationships is central to her story. She remembers how her brother would "take my alcohol, my beer, and put it down the sink when he came into my... my mother's house". Tina said she would just go drink elsewhere. Sometimes, she would ask for money on the street to buy alcohol. In her late 40s, Tina was found collapsed and very sick on the floor of her apartment by her fiancé. He quickly called 911 and she was rushed to the hospital only to find out that she had liver damage. "The doctor wondered why I was still living with all the alcohol I had in my system".

Tina was mandated by the court to live in her group home "The court put me here for the rest of my life, until I die. Yeah, and I put myself here" and a social worker helped her to make the transition to living in her current home and community. She described her positive feelings towards this worker "And [worker] helped me a lot. Like when I was hospitalized, put me here, and took care of me when I was sick in my room, and like when I was throwing up. She helped me out a lot, [worker]. She's like my mother. Yeah, mother, I don't have anymore". Before this point in her life Tina was not helped by any services or workers.

The impact of decades of alcohol use were major for Tina. She lost contact with her siblings and their families who she feels "They don't know where I am and I don't think they wanted to know where I am". She proclaims "I have no family right now. My mother passed away. My brothers, and I got three brothers and a sister, I don't see any more either. [Worker] doesn't know where they are. I don't know where they are, who knows". Tina described her mother, with whom she lived until the age of 21 or 22, and then afterwards lived next door for some time, as someone who "helped out a lot".

Tina spoke only briefly about her childhood and her experience of school, as she did not remember these early years very well and chose not to speak about it. In reflecting back on her story during the final conversation she had with us, Tina mentioned that her father had been an alcoholic. Regarding her early schooling, she said simply that she had been a shy person who did not talk much to her peers and had few friends. School was difficult for her because she had challenges with reading and writing, which is still true to this day. She mentioned that she needs

help to read documents. Because of these challenges, Tina stated that she was always unable to work and relied on welfare payments to survive.

At the centre of Tina's story is the love she has for her three children all of whom are now adults. Her eldest daughter is D., and she has twins, a boy and a girl, named P and L. They are all now in their 30s. When D. was born, Tina lived with her mother for a short time and described her mom as a source of hands-on help and support. When D was still a toddler, Tina took her and moved in with "a guy I met". Because of her alcohol use, the man called youth protection services and as a result, D. was placed in foster care. When her twins were born, they too were placed in care, at birth. Losing her children is the hardest thing that Tina has had to live with all of her adult life. She experiences the fact that they were taken from her and lived elsewhere (in foster care and group homes), and that she has had very little contact with them, as heartbreaking. Tina speaks about this great loss with regret and remorse. She frequently described herself as a "bad mother" during the interviews because she was unable to care for them when they were growing up. Still, she recognizes that she was not in a good place to take care of them "Yeah, I did bad, I was a bad mother... it was sad for me. Happened 'cause I didn't take care. They were better off where they were, too". Tina longs to be in contact with them again "I wish I could see my kids now. I wanna see them. I really miss them".

Tina returns time and again to the love she has for her children and to the great loss of losing them to child protective services. Even as she describes other meaningful moments, ideas, or people in her life, she returns to the subject of wanting to see them. For example, when asked about her feelings about aging, Tina told us "I feel that I'm getting older because it's part of life. And it's part of reality, and part of life. Like, I'm gonna be 60, I'm already 60 - I'll be 61. I was born [date], so I'll be 61 this year, in [month]. Yeah, I don't look it, eh? No, I feel like old lady. ...just physically... I just feel like old lady 'cause I'm getting older now. And I can't see my kids".

Tina recounts the time, in June of 2019 when she traveled to another province to be reunited with her son and meet his partner. It was an important moment for her, and not only did she get to see her son again, but he also told her that she was a grandmother. Her eldest daughter D. had a boy, and though she has not met him, she speaks with pride about having become a grandmother. Unfortunately, both Tina and her workers have not been able to contact him again. Tina mentioned that she tried to call him several times but could not reach him.

Aside from her children, the other love of her life was her fiancé D. who she was with for over 20 years. She identified how "... he helped me a lot with some guys that just weren't healthy. They just, they wouldn't care so much as he cared about me. Now I wish he was still here. He was the best for me...". She met D. when she moved into a low-income apartment building in her 30s and he lived in the same building, working as the janitor. They spent many years together, always supporting and loving each other. After she had collapsed and he found her on the floor of her apartment, D. called 911. When the social worker at the hospital told her about moving into a group home, D. encouraged her to make the move, so she could get the support she needed to quit drinking and take better care of herself. He visited her there several times. Sadly, D. passed away not long after she moved. Tina did not find out about it right away but had a feeling something was wrong when she could not reach him. In speaking with her support

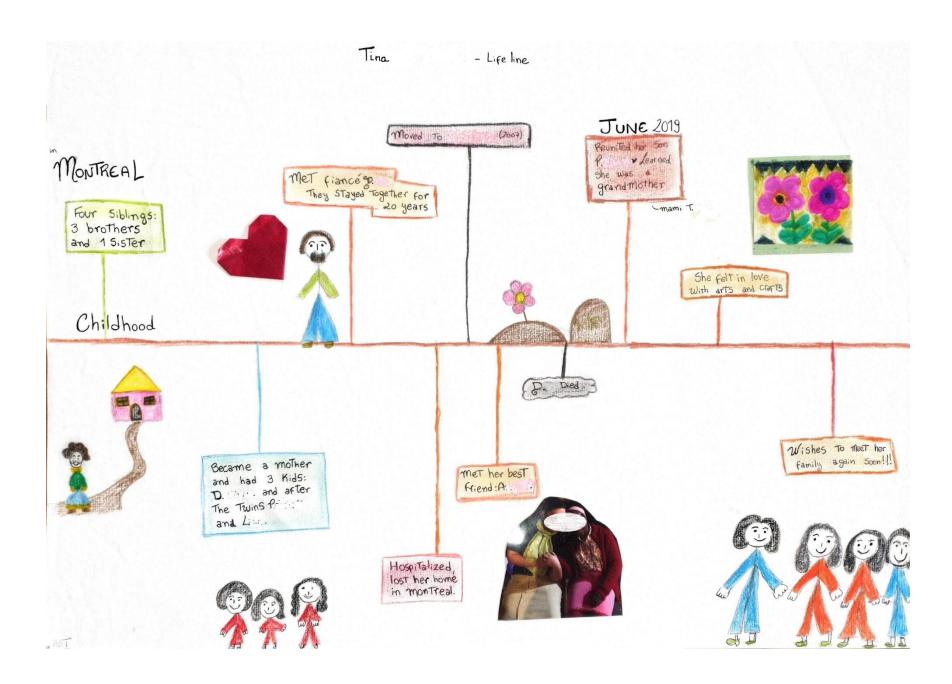
worker during the interview she said "I really like it here and it's a good place for me to be here and it's okay. The first few years, I was not so good to me 'cause I missed my fiancé and I wanted to be with him, instead of living here. But I realized when, when, when I came here, 'cause you told me after a while after that he passed away and then I didn't want to eat or nothing and be by myself in my room. That's the way I felt inside, to myself". Thinking back, she regrets that they never got married.

Tina told us that her mother passed away before Tina moved into the supported housing community. She regrets not having been able to see her when she died. "I just realized when I came here that she had [already passed away]. Then after I, I felt real bad. That I didn't get to say nothing to her before she passed away, but it is part of life, and I have to accept it that's she's not here anymore". Although Tina is, at times, uncertain about the dates of these important and sometimes tragic moments, the feelings of loss, and of gratitude, particularly for the over 20 years she shared with her fiancé, run deep inside. She speaks of her continued relationship with her fiancé despite his passing as she shared that she still talks to him every day, like she always did. She misses him but is reminded about how special their relationship was. "And I really miss him. Yeah, he was the only one who cared about me. Nobody else in [my province]... I had a long life with him when he was still here, though, 'til his time came, that was the best. The every little day things that mattered".

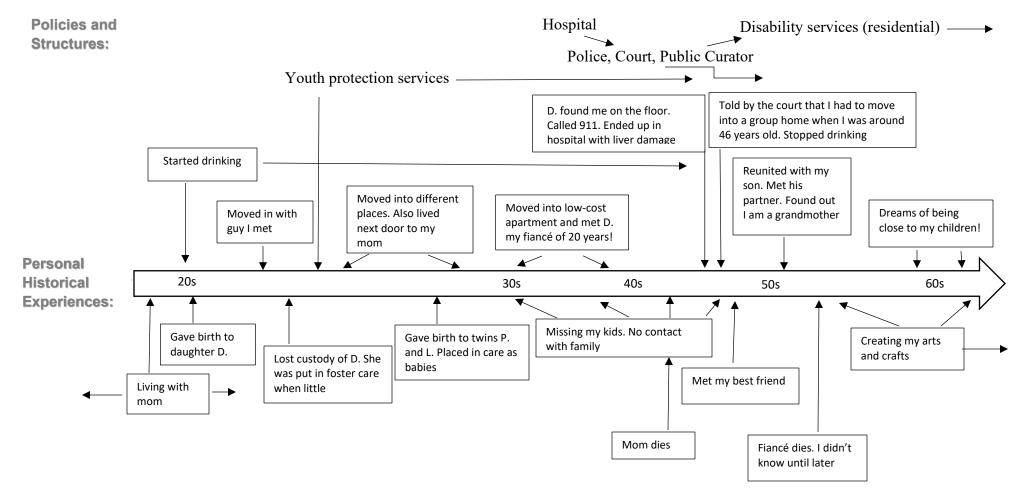
Despite all the challenges Tina has faced in her life, she still has a bright smile and a positive attitude. She loves doing arts and crafts projects and enjoys baking. At her group home and in her community, she actively participates in activities. Her room is filled with photos. From the walls, pictures of her young children and her fiancé smile back at her. Tina has an art display wall where she hangs her art projects and she shares this with great pride. She loves music and has many CDs of her favourite singers and bands. She loves shopping and says "And [my worker] said not to go shopping too much. I love to shop and I don't know why! Lot of stuff, lot of clothes and that in my room and I still want to go shopping".

Tina shared her daily routine with us, describing when she gets up, has her cigarette and then her shower, and stays quietly in her room until breakfast as is required so as not to disturb others too early in the morning. She spoke of the workshops in which she is currently involved and shared a story of previous visits from the dog that lives close by. She also describes the contributions that she makes within her community "Sometimes I knead bread dough and that. I make granola for the houses and that. And bring out the recycling, the garbage, the compost, the chicken bucket. I bring all that, away. Yeah, I'm going to clean up after that. That's what I do too ... I have cooking too. Where I help out set the table, doing dishes and cleaning the floor and cleaning the counters, and I clean the table, and that too". Although Tina shared some ambivalence about some aspects of her current living situation, overall, she states that she wants to stay where she is, that it is the best place for her so that she can get the help and stability she needs. On her own, she says she "would not make it". But she has a difficult relationship with one resident who she does not like which causes her stress and tells us that she must go to church every Sunday, which is "Too bad 'cause I'm not into church. I have to go every Sunday. But I don't like it, but I have to go. That's life, yeah. Yeah, [everyone] goes. Dress in nice clothes, and nice skirt, nice top, and nice tights, nice shoes. And because it's a service, dress in all nice clothes. Yeah, that's what I did. That's what we did. Oh, it's okay. It's okay, I got it. I'm used to it now since I'm staying now. I'm living

there now. Yeah, I don't ... wanna live nowhere else. I like it here at [residence]". Tina's attitude is one of acceptance and she tries her best to do what is expected of her and to ignore the difficult resident with whom she does not get along. Happily, Tina tells us that she has made a best friend in the community who lives in one of the group homes nearby and they talk frequently and listen to music together. Each week, they walk together to attend church. This good friendship is something she cherishes. Tina dreams of meeting someone, though she says it is likely impossible given her living situation. She also wishes that a dog or cat could live at the home because of her love for these animals. But most importantly, Tina hopes and waits for the day that she can be reunited with her children, especially as she grows older. "What I want in life? Well, I want my kids again, that's all I want".



Tina's intersectional life line



Agency Identity:

mother - grandmother - fiancée - friend - artist - baker - cat & dog lover