

*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*



Dadou's Story

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Dadou's Portrait

Dadou is a 73-year-old woman who grew up in Montreal with her parents, brother, sisters and her “gang”, her group of close friends with whom she went out often. After high school, she took business classes and worked in accounting until she married in 1973, at the age of 23.

Her first child A arrived a year later, a little boy who changed the course of her life. Seeing that he wasn't walking at the age of 16 months, A's pediatrician referred the family to a neurologist, who confirmed encephalopathy. The diagnosis was difficult news for Dadou's husband. As for Dadou, she simply “embarked on the wheel”. Dadou quickly became a “regular” at appointments, consulting many specialists in order to help her son improve his physical abilities. When A reached the age of two, Dadou became an active member of a parent association, beginning her path to activism for the rights of neurodiverse people.

Eight years after the birth of her son, Dadou's daughter L was born. Noticing that L was reaching developmental targets more quickly than her older brother, Dadou and her husband did not initially suspect a developmental delay. However, as the months passed, L's progress stopped improving, causing concern for her parents, who then consulted a neurologist. At the first appointment, the neurologist did not offer a conclusive answer for the parents. “We'll see you in 6 months”, he said. Dadou described this period as “the worst 6 months of my life”. Realizing that her daughter was still not making progress, Dadou recounted, “The waiting was worse than knowing”, explained Dadou, who finally received a diagnosis for L after 6 months of waiting. This time, it is Dadou who is most affected by this news because of the many questions that this situation raises, “You can't imagine what your life is going to be like”. With issues related to neurodiversity being less understood at that time, Dadou and her husband lived each day with uncertainty about the future.

When the children reached school age one after the other, Dadou remained very involved in their lives. Since A and L attended specialized schools, they had access to many professionals on site, thus there was little need to travel for needed interventions. For a few years, the family also received support from a rehabilitation center, as well as home-based services a few times per week. However, the burden on Dadou's shoulders remained heavy given A's behavioural problems, which “hurt me a lot in life”. While her husband sometimes intervened with the children when they were younger, “after that, when the problems got bigger, it was always me”. Her husband worked long hours, “maybe he was working a lot so he wouldn't have to live with it”. Dadou explained that she didn't “...dare to complain because I know he would have told me ‘Just place them’”. Despite the difficulties, the couple stayed together for almost 20 years, until their divorce, which Dadou describes as leading to a sense of “peace”. Indeed, she had “one less to worry about”. While the father continued to contribute financially to the family until his death in 2018, Dadou was the primary day-to-day support for her children. Two years after her divorce, Dadou returned to work and found a part-time job in food services at her children's school. She appreciated the flexibility of her schedule, which allowed her to take care of her children while working. She worked for 20 years, first in the cafeterias of the schools her children attended and then in other schools across Montreal.

Over the years, Dadou faced challenges related to services and systems for her children. When

her son's behavioural problems were deemed too severe for him to use a taxi service, Dadou took on the role of driver from the South Shore to Montreal every morning and evening until they moved in 1987. She also found companions who could support her children and allow them to develop and grow through outings and activities. A and L worked in various workshops after high school, work that A particularly enjoyed and that Dadou also appreciated. Dadou recalled interactions with various community workers, who were impressed with the quantity of activities her children had access to. Dadou shared, "She thought it was the resource that organized it. Ha! No, it's Dadou". Dadou would like to be able to go out once in a while, "We need to have a little break... We need to be able to breathe". However, she expressed that her moments of rest are often marked by guilt, because "I can go on vacation, but they can't. They are at home doing nothing".

Dadou's impressive community involvement stemmed from a lack of services for individuals with neurodiversity. After high school, A lost many aspects of the support system previously provided by his school. Unable to find respite services, summer camps or babysitters, Dadou decided to place her son in a community residence. Soon after, the CRDI closed the majority of their community residences. Of the 32 residences, only 9 remained, which all became specialized assisted living residences. Dadou pointed out that this meant a step towards privatization, which was worrisome for her and the parents' association. A is now in a specialized continuing care residence, where educators help him work on his behaviour so that he can eventually find a place in an intermediate resource. Once this goal is achieved, Dadou still has "a full-time job", whether it is managing unpredictable events or ensuring the quality of her son's life in a residence managed by "Mr. and Mrs. everybody" who "do not necessarily have the skills". Faced with many recurring problems, particularly related to hygiene, Dadou noted, "they wouldn't do that for their own children". When her daughter L moved to a residential resource shortly before COVID-19, Dadou's care work continued. For example, Dadou continues to advocate for her daughter's nutritional needs to be adequately met and decorated her room which is "cold, neat, dry". For Dadou, "there's always a way [to make things better]".

As well as being a parent, Dadou is involved in defending the rights of other users living in her children's residential resources. Having been involved in user committees for many years, she advocates for the well-being of all individuals in these types of resources. She shows a lot of empathy for users who do not have a family and for "parents who are not able to defend, who are afraid of being cut off from the services they have, or who are aging". She remains firm about defending rights. When the priority is reducing waiting lists and not providing adequate services for users, Dadou does not hesitate to express herself to the people in charge who are "there [simply] for their job and not for the users".

Through her involvement, Dadou met other members of the committees she's a part of, including other aging parents who are in a situation that is similar to hers. Her own family is also important to her. Dadou spends every other weekend at her sister's house and is now closer to her. Dadou had a friend with whom she was "very, very close". She described this friend as someone who was "aware of all my emotions, and my things". Both Dadou and her friend had children with neurodiversity and "we never felt sorry for our children either". She said that they shared freely about their feelings and situations. Dadou explained that since the death of this friend a few years ago, "I live my emotions, my things, alone a lot". Dadou shared

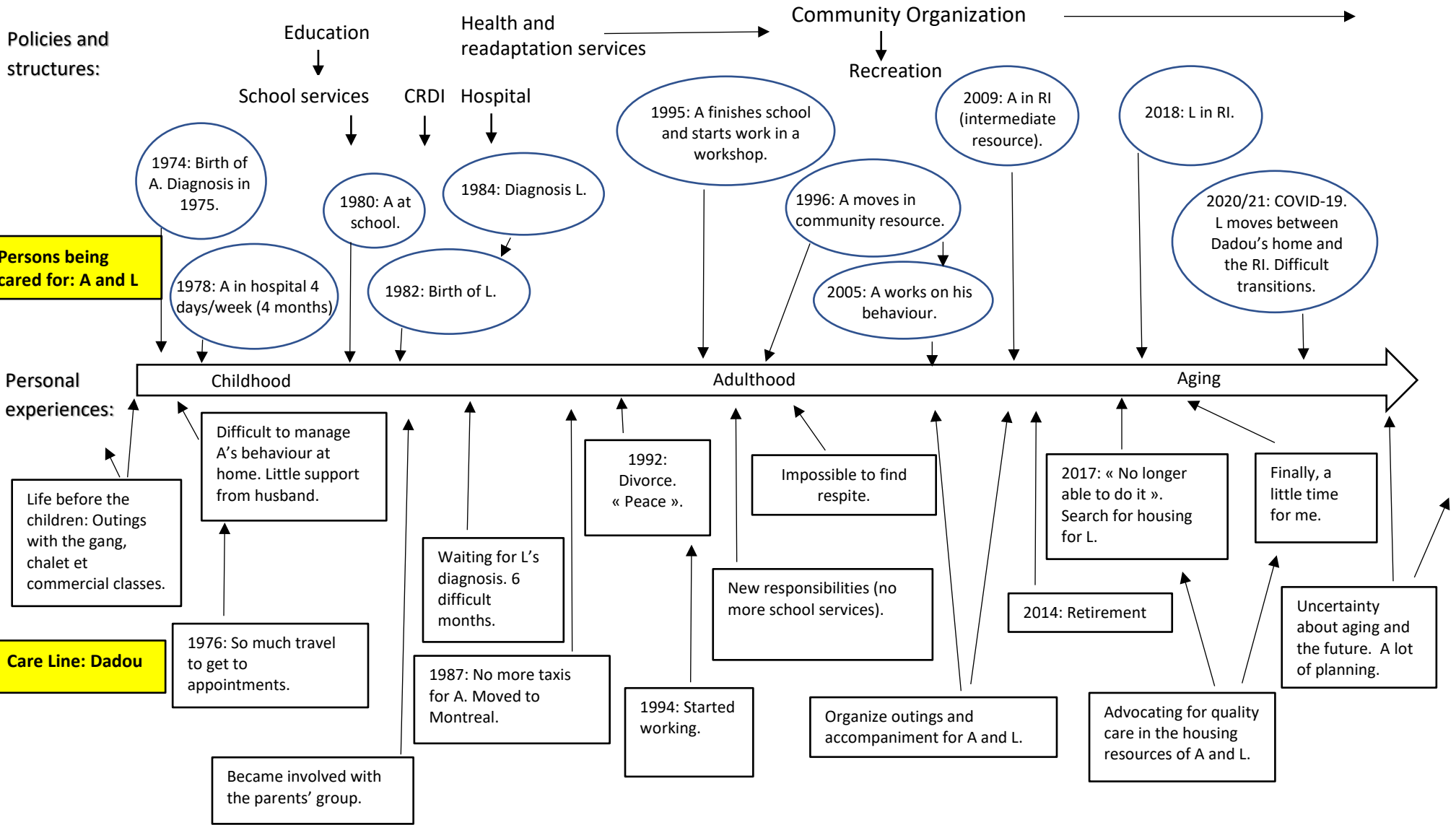
that she is used to the difficulties that her role as a parent present, "...I'm rolling with it and I say to myself, well, that's life".

Dadou leads a very busy life, where a few moments of rest are rare and precious. These days, she can only find time for herself a few evenings a week. On these evenings, she does not usually seek to go out, but rather to find "peace". For her, this often includes a quiet evening when she can "hang at home" with her cat and dog without being asked to do anything.

A major concern for Dadou is aging. She shared that she feels strongly that "the future is not rosy". More precisely, she has uncertainties about L's future. While she has identified a future guardian for A, someone who "knows him very well, and is already involved in his life", L does not have someone as close to her who can take on this important role. Dadou is also an important emotional support for L, who battles anxiety. Dadou expressed that she does not expect anyone else to be as involved in her children's lives as she is, but that it is important for an eventual guardian to be someone she trusts and who is close to her children. Dadou explained that aging involves "a lot of planning". In addition to her will, Dadou wrote down all her wishes for her children's futures, ranging from the activities she would like them to pursue to the name of their hair salon... "There are so many pages". Otherwise, "the day I'm gone, L will fall into the same pattern as the others". Dadou relates to many other aging parents who also experience similar concerns, "We're in this, [and as time goes by], it's certain that we create a bond".

For now, Dadou plans to stay involved with her community for as long as possible. The well-being of her children and all other service-users is a major source of motivation for her. Dadou ended her interview by exclaiming "I have a passion for sure!".

Dadou's Intersectional Care Line



Agency Identity :

proactive – empathetic – advocate – devoted – competent