

*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*



Audrey's Story

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Audrey's Portrait

Audrey is a 56-year-old woman, born in France. When she was 1 year old, her family immigrated to Quebec. She lived in the West Island of Montreal where she completed her studies in adapted classes and has forged friendships that have persisted over time.

Audrey has lived a life of successes, challenges, and transitions. She has experienced multiple and sometimes complex disabilities, some of which are congenital and others which appeared in adolescence. "Vision and hearing yes, alopecia is not too bad because it doesn't prevent you from working, it doesn't prevent you from doing these things, but vision and hearing when it is there, you don't have a job, you don't have anything". As an adult, as her hearing continued to deteriorate, she agreed (over time) to wear a device for the first time, and she heard the sounds of nature for the first time. It was a defining moment for her: "...I could really hear the ocean; it was the first time I really heard the wind in the trees and all that...".

Audrey also experienced changes in her environment at different times in her life. Notably, living with other people (roommates and parents), in a semi-supervised apartment, in a group home, and living alone. She considers that living alone and being independent is the most satisfying situation because she can make her own decisions on a daily basis: "You can do whatever you want, you can fall asleep in front of the TV and nobody can say anything". Audrey exclaimed, "to be in your own apartment... that's freedom".

Over the years, Audrey has experienced various social relationships within and outside school and socio-professional environments, from formal and informal networks. Throughout the interviews, she described the difficulties she faced during her schooling, as she was often bullied at school and constantly reminded that she was different. "Yeah, it was tough, that's for sure. It was like, not obvious... you're there, you're different, you're trying to fit in. But there are some who make your life more miserable than it has to be, for real. It's not obvious, but there are children who are in schools, and they don't need to be disabled to be punching bags (laughs) for other bullies". Despite the denigration she suffered from her peers, Audrey showed empathy towards them: "...I don't know what these people have had, maybe they have had a different life afterwards, I think maybe those people who hurt others in their youth, maybe they lived after that...oh, their children were different, and we know that, we don't know anyone's future".

Audrey also participated in different professional and recreational activities and talked about places where she felt excluded due to her disability and others where she felt a sense of belonging. "Yeah, yeah, yeah... but it was very funny... it's like, it's a place where I really, really liked... I was comfortable, I was like... I felt like I belonged there. Although I also have... reduced mobility but differently... but for example, I felt good in that environment, we made friends, we made friends... and then we also learned things about them that you can't imagine...". Audrey said that what is most important to her is that her daily activities, whether professional or recreational, provide her with meaning and fulfilment. "For me, it's keeping myself busy, but not really with work, but keeping busy...especially having fun in what I do, even if it's just activities to get me out of my house. Having like other things to talk about, other than only from home".

Audrey benefited from the support of many workers from government and community organizations. Referring to a community organization where she has been a client since the age of 18, she described: "it's like my second family". For Audrey, the change of worker is experienced as a significant loss. "What happens is that you want, you don't want, when you have worker, you get attached...we talk to them, we entrust them with things...when there is a change, it's as if you've lost a friend. At some point, over time, you continue to confide in yourself, but you no longer have this tendency to develop a friendship. I lost a lot of them that I was close to, so it hurts, some even invited me to go to their house and everything, I met their children...it hurts, as if you were losing a friend, it's simple...". Despite her independent nature, she recognizes the importance of the support she receives to achieve her goals, "having help helps me to have a fulfilling life".

Audrey's friendships are very important to her and the loss of her friend when he was 59 years of age was also a difficult reminder of her own aging. She tries not to think about aging, but seeing her parents grow old reminds her that she's getting older too. "Well my parents are getting older...yes we try to avoid thinking about it uh...we try not to...ok of course I see them their hair going white there, you know it's like try not to think about that there... you go there and you say it's, you say good very nice...otherwise if you start thinking about them like they're going to leave, you're going to be...you I know it's going to be unfortunate... of course they're getting old, you're getting old so they can't help but grow old...". Despite some of her difficult experiences, Audrey considers that these moments have shaped her personality and that ultimately life "...is fun".

In her thirties, despite the announcement of new physical health conditions, Audrey learned to manage in order to remain active. In particular, she is involved in the users' committee of a health establishment in order to defend rights and propose changes to improve services for people with neurodiversity. Audrey affirmed, "Yes, I think we should be looked at as people...well, I don't like that word...'normal' people, I would like them to look at us like, we are given the same services, that don't use big words so that we don't understand. So, I would say that to the people who are going to take care of us. It's a great effort on their part, but for us too, because it would be easier for us to explain and afterwards, to feel understood. It's important that we feel understood, when we talk to a doctor or a nurse, to say that "I have an injury there" or "it's the little blue pill". It's fair to say, to show us well, like with the things they have at the pharmacy...".

Through her involvement in various community organizations, she discovered many passions, including painting, and forged meaningful relationships with peers. It is at 50 years old that Audrey lived one of the most beautiful moments of her life; she became a Canadian citizen. "Yes, it was a big step, then I really felt...even if I have been here for a long time, almost born here, for me it was home. I think that's what helped me a lot, I was at home, went to school here, spoke the language of Quebec, and also of Canada, which is English. Look there, it's our home, it was just to have it on paper (laughs). I could have done it at 18, but I was like, "oh no, I want to keep my French nationality". I didn't have the same ambitions, because I was young, and I was from Quebec, and after that, as you get older, you realize that many things change...". She learned and developed wisdom through the friendly relationships she maintains with people older

than herself. During the last meeting, Audrey announced to us that she had just moved to a new apartment in a social housing unit. For her, it's a dream come true. She will finally be able to be independent in a larger apartment in which it will be possible to grow old comfortably and prepare for retirement. Despite her apprehensions about aging, she maintains a peaceful and positive attitude about what the future holds for her.

Audrey

Ma Ligne de Vie

Les évènements importants qui m'ont marquée

ARRIVÉE AU CANADA AVEC MES PARENTS EN 67 J'AI 1 AN ET 8 MOIS	J'AI ÉTÉ AUX ÉCOLES PRIMAIRES EN FRANÇAIS DANS L'OUËST DE L'ÎLE DE MONTRÉAL. CLASSE SPÉCIALE. PROBLÈMES D'APPRENTISSAGE ET RENCONTRE D'UNE BONNE AMIE	MES ÉCOLES SECONDAIRES 1, 2, 3 2, 4-5 DANS L'OUËST DE L'ÎLE EN FRANÇAIS. RENCONTRE D'UNE AUTRE BONNE AMIE TOUT LE LONG DU SECONDAIRE	A 13 ANS S'APPREND QUE JE SUIS MALADE TENDENTE.	A 20 ANS 1 APPAREILS AUDITIF 2 SE REUSSIS MON DIPLOME DE PRÉPOSÉ AUX BÉNÉFICIAIRES ET TRAVAIL DANS UN CENTRE DE LONGUE DURÉE.	A 24 ANS, J'AI HABITÉ À A PENDANT 3 ANS MES RENCONTRES AVEC MES NOUVEAUX A MIS ET REDUR SUR LES BANCS DÉCOLE S'AI REPRIS MON SECONDAIRE	RETOUR SUR LE MARCHÉ DU TRAVAIL / STAGE
RESTE À LA MAISON AVEC MA MÈRE MON PÈRE EST AU TRAVAIL.			A L'ÂGE DE 7 ANS, SE SUIS TOMBÉ EN MALADE. PROBLÈME SANGUIN.			JE SUIS MEMBRE DU COMITÉ JUSQU'À
A L'ÂGE DE 32 ANS S'APPREND QUE JE SUIS 1) DIABÉTIQUE TYPE 2 GÉNÉTIQUE.	DANS LA QUARANTAINE JE ME SUIS INSCRITE AVEC L'AIDE C. AU CENTRE	A L'ÂGE DE 50 ANS, SE DEVIENT CITOYENNE CANADIENNE, MA PLUS BELLE REUSSITE!	A MES 55 ANS JE PERD MON AMI BON & VIEL AMI N'AVAIT QUE 59 ANS UN A.C.V.			
2) QUE J'AI LA RÉTINITE PIÈGEMENT TAIRE.	POUR DES COURS DE PEINTURE (ARTS) ET COURS D'ORDINATEUR.		MON BONHEUR SE VAIS VOIR MES VIEUX PARENTS POUR NOËL			
3) QUE JE SUIS MENOPAUSE. ET RETOUR HABITÉ 1 ANS À A.						

Audrey's intersectional life line

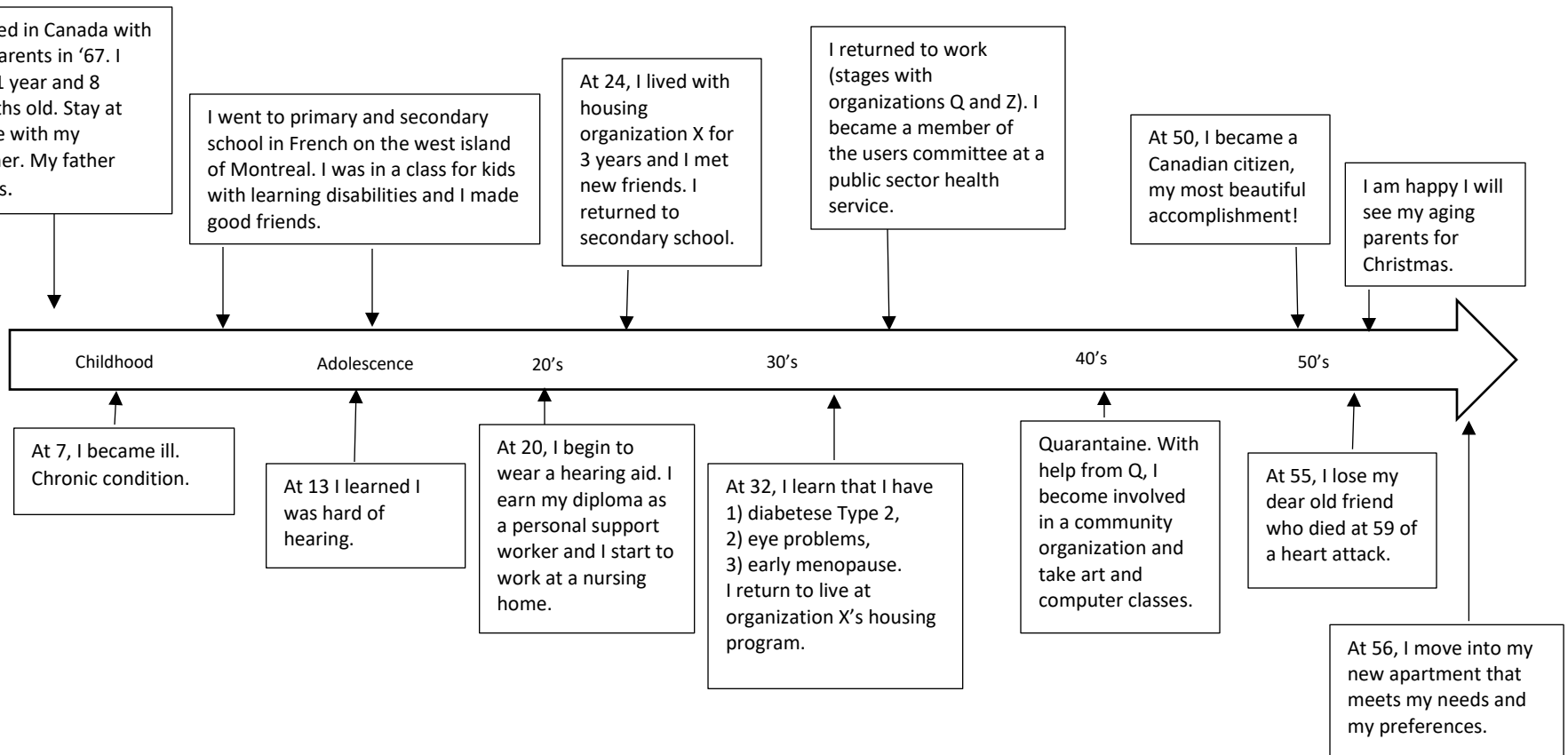
Health and social service system →

Policies and structures:

Immigration →

Community organizations →

Historical and personal experiences:



Agency and Identity:

independent - friend – active - client – artist - hockey fan - optimist - humble