

*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*



Luce's Story

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Luce's Portrait

Luce is a 61-year-old woman who lives in Montreal with her husband, whom she calls “my kindred spirit”. With the support and encouragement of both her husband and sister, Luce has acted as the primary family caregiver to her older brother for almost 14 years. Luce began her story by sharing that she grew up in a loving family. She is the youngest of three siblings. The eldest sibling is her brother O, who was born in 1955 and who lives with disability. Luce’s older sister P. was born in 1959 and is the middle child. Luce asserted that she has “always known my brother” and that the family dynamic was “already there” by the time Luce was born.

O was first evaluated for developmental delays in early infancy and was diagnosed with intellectual disability and Cerebral Palsy. Beginning in childhood, O had challenges with fine motor skills, personal hygiene and bathroom function, reasoning, and sometimes experienced tantrums, which made hands-on care and supervision part of the family’s daily routine. Luce felt that because O “required a lot of attention”, she and her sister “grew up very fast”. Luce remembered the time when the professionals involved in his treatment decided, at the age of 16, that O needed to go to a psychiatric hospital after it was determined that he already “took everything he could” from his previous “special school”. Luce explained, “...in 1970, they did a 360 where they... wanted to understand how much more he was going to learn, how was his development and what kind of care he would need... to get to the maximum of his potential, so they... confirmed that he had Cerebral Palsy and that he had limitations when it came to intellectual development and that's when they determined that if he stayed at home that he was not going to thrive, because he was overprotected... he was not going to be able to become autonomous”. For about 10 years, O spent the week in the hospital and returned to the family home every weekend. This was a challenging time for the whole family, especially for O who, though “resigned to the fact that he had to stay there, was sad to leave the house” when he was taken back in the car by his parents and siblings each Sunday. Luce described these trips to drop him off at the institution as “...hard, heart gutting...” for her parents, her sister and herself. Nevertheless, reflecting back Luce believes that it was the “right thing to do” as “it was understood at that time that he needed to move on for his own good so that he could become autonomous”. Becoming more autonomous was a motivating factor for O who was determined to be more independent and to be able to live on his own where he could control his own daily life choices, schedule, and activities. Luce shared that “...he wanted to do his own thing, didn't want to have any kind of restriction as to when he came in, when he left, what he ate, you name it. So, he succeeded in becoming more autonomous, but at the same time we always were involved... he came to my family, to my parents’ place... he always stayed connected with us...”. O was eventually able to leave the psychiatric hospital and experienced several housing transitions including living in family type resources before finally achieving his goal to live in his own apartment. The apartment he stayed in for many years was situated above a pet store, which was a good location for O because, as a “night owl”, he could play his music and walk around his apartment without disturbing neighbours. O had frequent supervision each week from service providers to help support his hygiene, cleanliness and to ensure he did not “keep everything” (Luce, II, 364) in such a way as to clutter his apartment and for it to become a safety risk, as he was prone to hoarding.

Luce recounted that the most difficult decision her parents had to make was to put O under protective supervision with the Public Curator at the age of 18. At the time, doing so was the only way to ensure his eligibility for services. Luce declared “[It] was the worst, the most difficult

decision that they had to make. But if they did not do that, they could not have access to any services for my brother, who [was] getting to be 18 years of age and then there's nothing for them, right?... My parents remained very much involved... my brother would come every weekend to see them, but he would be in an environment that would help continue to support him and provide the services that he could not have had, had he remained within the family unit”.

Luce spoke lovingly and respectfully about O’s many strengths during the two interviews. For example, Luce stated that O “knows the transit system... more than anyone in the city” and is “so smart in so many ways”. Luce said that O’s situation was very unique because “he is very witty, so that is actually something that would frustrate my father very much because how can he be so strong in so many ways and then at the same time not have the reasoning... it was always such a contradiction in the way that he was so smart in so many ways and at the same time he had those limits that made it even more of a challenge. There is a limit to his reasoning, and he has his own way of thinking you know, so we have to adapt to that”.

Luce described O as very social and friendly, willing to talk to everyone and making lasting connections in the different settings he had been in. For example, he spent a few months in a rehabilitation center where he received support after he broke his hip. Luce declared “at that time he was thriving, he had his meals, he had physical education like he had to, you know he loved it, there were all sorts of activities”. This was a place he wished he could have stayed at longer. Despite being discharged, O returned to visit there to keep in touch with people he had met as “he basically connected with them and decided to adopt them and vice versa”. Luce also described that O was very skilled in getting his needs met over his entire life, and would often approach family, people in his various networks, and even sometimes strangers, to ask for help. According to Luce, this was both a skill and a challenge, because sometimes it meant that O “...goes to people who will have the humanity, and the ‘bienveillance’ to take care of it, so he’ll go back to them all the time for that”. Luce shared an example of a woman who worked at a gas station near where he lived, who had been in foster care as a child and so “could connect with O”. O would go to visit her regularly and if he asked her for help, she would try to support him. Speaking about herself and her sister, Luce shared that “...he has a little bit of trembling in his hands, his coordination is affected and anything that needs precision, he has a very hard time doing, so he would need assistance for us to do things for him. And also, because he would, it would be easier for him to ask somebody else to do it, he would not necessarily do it on his own unless somebody instilled him to do it, so for a young daughter to have this kind of pressure already, to always be there for her brother it had an impact. ... I never knew anything different you know, my sister either, but we became support systems for my brother very early in our lives. My parents sat us down and explained the situation because it was difficult as a child”.

Things were not always easy for Luce growing up. In her early childhood, Luce experienced different illnesses that kept her home from school, and so her mother’s attention was divided between her, and O. Luce reflected that this was probably the hardest on her sister, who was “in the middle”. Luce shared that she coped by eating. Food became an outlet for her, and it was at its worst when she was a teenager between the ages of 13 and 14 years. Luce’s relationship with her sister also suffered, as they coped with the situation at home differently. Although Luce “wanted to have a sister in [her] life” it wasn’t always easy. However, since their parents have passed away, Luce said that she and her sister were able to reconnect and now have a closer relationship.

Luce shared that her parents wanted her and her sister to be independent women and cared very much about their education. Although she was initially set back in school because of being sick, Luce described how she “really blossomed by the time I got to CEGEP and university”. After that, Luce excelled in her career as divisional director with a national company. In 2015, Luce was diagnosed with breast cancer. After undergoing treatment successfully, Luce decided in 2017 to take time to think about her work-life balance. She told us “...my husband was taking his retirement at the same time, so I took a pause between 2017 and 2020 to reflect and say, OK what am I going to do and take more time to get better. I was cancer free at the time, but it scared me and I took a pause and then decided... I volunteered for a couple of years before going back to work part-time and doing something I enjoy so much [working at a retirement home]”.

Luce described her parents as “they worked together, they rolled up their sleeves and they made sure that we stayed a unit that was going to be taking care of each other and they stayed, they stayed together until the very end”. She explained that her parents “were very much in love, very united” and although having a child with a disability can be difficult, in their case “it unified them”. Luce’s mother was “the key touchstone, the caregiver” for O until her death in 2009. She was extraordinarily involved as a caregiver in the early years when there were no services available. Luce’s father was a doctor, and worked a lot, so she didn’t get to see him much in her childhood. With his knowledge and expertise in medicine, Luce’s father helped to ensure O received a proper diagnosis and treatment and was involved in medical and administrative decisions throughout his life. Luce shared that, in her adult years, she met many people who worked with, and knew, her father. Luce feels that she “really got to know him much more” (Luce, 11, 37) because of these encounters and affirmed that “after 11 years of his passing, [I] still hear so many great things about him, it's really great”.

Throughout her life story, Luce recounted both the triumphs and struggles of having a sibling with a neurodisability. Luce told us that it was sometimes difficult for her, her sister and her parents and at times, she could be frustrated and impatient with O. Luce described different examples of how her brother’s needs became overwhelming and reflected upon one meaningful moment in the 1980s when her parents, sister, and she had a meeting with a service provider during which she was asked how she felt for the very first time. Luce reflected that living at home was sometimes difficult, as she didn’t always feel comfortable bringing friends over and that, even within the family unit, it was hard “being subjected to an environment that was stressful because everything was focused on him”. Luce decided to move out of the family home after her graduation from university at the age of 24. Luce declared that she really wanted to “have my freedom and to be in my own space, my own apartment”.

Luce met her first spouse in 1989 when she was 30 years old. She and her spouse moved to England where he wanted to pursue a job opportunity. Luce spent her time abroad volunteering, taking computer courses, and even applied to university to pursue her MBA. Luce told us “my common-law spouse at the time said ‘well I have an opportunity, and why don't we just take advantage of it and go’, and before we left, even way before then, he knew that my brother was going to be part of my life and that if I decided to go to Europe, that it was only for a certain period of time, because I would eventually need to go back. So, I said ‘let's do three years and we'll take it from there, but for sure I'm coming back to Montreal’”. Luce admitted that this was “one of the reasons why it didn't work out”. Luce explained that her former spouse didn’t accept O. She recounted the time when he first met O and told her that he “can't stand this, this is not

something that I'm comfortable with". As a result, when he told her he wanted to end the relationship and move on, she felt relieved and "didn't fight it because I wasn't happy either".

Luce shared that she feels "deeply rooted" to Montreal and finally moved back from England on her own when she was 32 years old. "I met with a psychologist for many years during that period of time and it [was] the support of the psychologist that help[ed] me thrive and find my calling, my personal taste and interests. Because I never really thought of what was interesting for me, I was always thinking either [about] work, or my brother, or this and that... and I changed my career at the same time... but the psychologist support was key for me to find my own path... And after someone that is more objective is able to provide me with [an]other outlook, it helped me thrive, it helped me become who I am. It was key for me to go through the family dynamic... even at one point the psychologist said, 'are you able for a certain period of time to disconnect from your family, your brother, your sister, can you step away from all of them, not be so involved, so that you can focus on yourself for a while?' ...it was quite an enlightenment... I realized how much you get into the, the day to day not realizing how you get into a rut... and you don't think anymore... That helped me find my way... that's probably why I'm stronger now and that I was able to be open to find a relationship down the road".

During this time Luce discovered salsa dancing and explained that's where she "blossomed the most". It also became the catalyst for meeting her current husband, whom she married in 2016. In this relationship, it was important to Luce that her significant other had similar values to her and affirmed that he "has to accept my brother, he has to accept my family". Luce felt that the "circumstances with my first relationship [were not] conducive to having children" because "I didn't feel that my relationship was strong enough, [and] I wasn't going to bring in children in that equation unless I knew that they were going to have like a family unit that was strong". Luce shared that she loved and would have welcomed children in her life but that she was already 45 years old when she met her current husband, and so she feels fate decided she wouldn't have children of her own. Still, Luce has "no regrets" and she loves her two adult stepchildren who bring her a lot of joy.

After Luce's mother passed away in 2009, Luce promised her father, then 89 years old and unable to take on O's care, to always be there for her brother. Luce explained that "... in the last few years, especially since my parents have passed, I have my, my husband and I have been really the ones who have been very close to O for his, you know, day-to-day support. He would call us every, almost every other day, you know, to go back to his apartment, the TV didn't work, [or] he needs to change the light bulb, you name it, for any reason. He basically solicited us all the time; we were in his apartment at least 2-3 times a week. And we realized that the apartment was not clean, he was not taking care of it... And he's also a hoarder, which required the support [of the] 'intervenants' who would work with him on a monthly basis, to do a full clean up with him... which was always very difficult for him because he wants to keep everything, it's a safety, he wants to make sure that he's not gonna miss anything. I, we repainted the place, we changed the furniture, we changed everything to make sure that he was in an environment that was, you know, 'salubre', but then you come two weeks later... all the drawers would be completely upside down and then we have to start all over again...".

When speaking about recommendations for health and social care services for people aging with neurodiversity, Luce shared that she feels that no one is looking out for O. Luce worries about O's care, especially without anyone besides herself and her sister to advocate for him. She explained

that it's "unsettling for us as a family, because we're not going to be there forever... Because if something happens to us, I'm very afraid of thinking what would happen to him if we're not there". Luce shared that she and her sister created a trust and designated two friends and a cousin to take care of things when they are gone. She also wondered what happens to people who do not have someone looking out for them and stated that "it's as if they are left on their own". Luce believes that services are lacking in follow-through, and that there is no system to track "the evolution of the needs of a... of the persons who are under their care". Luce shared that it was scary to think that someone who is in a vulnerable position is at the mercy of the government's care from people who don't know them well because of the constant change of employees. Luce wishes there had been "an opportunity for us to have an annual review and support with psychologists that provide us with insight and tools to understand what the next steps are going to be, [what] you can anticipate that your brother is going to go through, and this is how it may impact you or what you have to look out for.... [But also] to know that we're all working in the same direction... that we're all understanding that what we do has an impact on what they're trying to do so that we're all working in tandem". Luce also shared "if there's one message it is if we are able to have more continuity and more communication between all parties that are involved in the care of a person with mental and physical disabilities combined, that would be such a relief for everyone involved and my brother would be the one who would benefit the first". Luce also mentioned the importance of community services and that the community worker M., who works at the organization in which O participates in activities, has become "an ally". Notably, Luce mentioned that she met M. for the first time at her mother's funeral which M., as well as several of the people in O's various social networks, attended. Luce shared that O has always kept his social connections separate from the family and explained that at the funeral "I see all these people coming to see my brother. Never met them before and ultimately on the other side the friends never knew he had a family like us. [I heard someone] he said, you have a brother, you have a sister, you have two sisters? You have, you have a father? And the whole family like the cousins and uncles. And so he really made sure that we didn't know each other because it suits him well. He's very smart, he's very, very intelligent and he knows how to play to get what he wants. That's probably a very good, protection mechanism to say, well, I'm going to get what I need and this is the way I'm going to get it and it's through sentiment, then I'll be able to get what I need. It's survival, it's survival and it's fine". In reflecting, Luce stated that she was grateful to have met M. and to be able to speak to her about her concerns and questions regarding O's situation and care.

Luce recounted how her brother had to endure many transitions in his lifetime including several changes in housing over the years. Recently, he has had to face new COVID-19 restrictions, and Luce shared that it has been difficult for O to adapt. Luce also described how aging has been challenging for O and reflected on how he "doesn't accept the fact that he's getting older. He finds it very difficult" as he has had to readjust to having reduced eyesight and motor function. Luce told us that "it's just in the last few years, where we realized that he could no longer be in that kind of apartment because he had some issues with... he fell at one point and he broke his hip, so he had to have a surgery. So, it became a little bit more difficult for him to walk... so it was a good time, it was good timing for us to say, you know what, maybe it's time to move on to another type of environment that will be safer for him". The final push came when his formal caregiver of many years, and someone whom O trusted, announced her retirement. According to Luce, "She [caregiver] told the government or the department that she was retiring in May and by July, we didn't know where he was going, and he had to move by August. So that became the emergency where all of a sudden, we had to find something and it was done without any planning, without any thought of the impact it would have on my brother. So that was the mayhem we had to go

through at that time. But then we were very lucky finally to find something. But it was all done in an emergency, where it could have been avoided”. Luce exclaimed, “He's 67 and although he did not want to move, he did not want to change, the change had to be made and it was too sudden... I really wonder sometimes had we not been as a family there to help him I'm afraid to think of how it would have happened, you know as far as the transition and to be able to help him move on to a ressource intermédiaire”.

Although the transition was difficult at first, Luce was glad to report that he now seemed to be settling into his new RI that he moved into in 2021, and Luce hopes that he can live the rest of his life there. Still, there have been some new concerns regarding the negative influence of one of the other residents on O that has led to some challenges of which Luce and her sister were only recently informed by the resource. This situation has only reinforced Luce's concerns about the lack of communication by the Public Curator and lack of care coordination by the system with the family. Luce thoughtfully, and with a touch of sadness, shared that “my hope is that we can take care of him” (Luce, I2, 537), and that she will outlive him so that he won't have to go through the same loss as when their parents passed away. A big part of Luce's life story is her brother, his care, and his well-being. She admitted that “my brother is always in my mind” and though she described an unbreakable bond, she and her sister also learned over the years that they needed to set boundaries with their brother in order to maintain a healthy relationship with him, to support their own health and well-being and so that they will have more energy to give in the long run, and as they get older. Luce ended her interviews by emphasizing that she has so much love and admiration for O, “as a person he is honest, he is witty, generous, very soft spoken... he has such a big heart”, and that she is very proud to be his sister.

Intersectional Care Line : Luce

Policies and Structures:

Community organization

School

Psychiatric Hospital

Residential services

Brother O.

Personal Historical Experiences:

born in 1955

was tested for physical and intellectual disability (1955-1958)

went to school where he learned to read, write, and developed his speech

psychiatrist confirmed ID and Cerebral Palsy

lived at home until he was 16 (no services available after school). Mom primary carer

moved to a psychiatric hospital to address behaviour and independence. Difficult for the whole family.

lived with *familles d'accueil* (mid 20s)

lived in a supervised apartment above a pet store for 18 years

Growing up, O went to sisters for help. Luce takes over primary role with help from sister & husband.

changing environment, having more restrictions due to moving and COVID-19 very difficult for O. as he cherishes his independence

O having difficulties in his apartment due to aging. Caregiver retires. Move to RI unplanned and rushed.

Aging has been difficult: reduced eyesight and motor function. Despite this, O still active and social.

1950s-60's

1970's-90's

2000-2010's

2020's - today

Eldest sister born in 1959

Hard for Luce to bring friends over, had to take care of herself

Luce feels that her and her sister "grew up very fast". Focus was on O

Mother passes away in 2009. Luce promised her dad to always be there for brother. Took over contact and care with sister.

Father passes away in 2011

Caregiver Luce

born in 1961

As the youngest, Luce feels she has "always known my brother" and when she was born, "the family dynamic was already set"

Luce, her parents and sister have a meeting with a service provider, who was the first to ask how she feels (1980s).

Luce moves to England with first spouse. They eventually break up and she moves home on her own in 1991. Seeing psychologist helps Luce to make life changes.

Luce met O's social his network at mother's funeral. Community worker M. became an ally in the care for O.

While O lived in the supervised apartment, Luce, her sister and husband have helped with regular support and advocacy.

Luce is concerned about how O. will be cared for as the family ages but is hopeful that he can remain in his current RI.

Luce meets her first spouse in 1989. She tells him "Eventually I'll have to take care of my brother". She explains this was "one of the reasons why it didn't work out"

Luce diagnosed with cancer 2015. Takes time to reflect. Chooses to work part-time at retirement home to have more balance.

Luce got married in 2016. Husband has 2 children.

Mom is the "key touchstone caregiver" for O up until her death in 2009

Agency Identity:

Sister - Strong - Caring - Independent - Self-reliant - Advocate