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PORTFOLIO

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*“You don’t have to leave me ... you can keep me
... We don’t have to die, we can keep living”
(Dona to Mimi)*

Introduction

Now, more than ever, it is likely to know a ‘Mimi and Dona.’

I met my first Mimi and Dona in 1984 when I started kindergarten in my home village in Flanders, Belgium. Looking back, a quarter of a decade and many demystifications later, I realize that ‘going to school’ at that age – for a ‘conventional’ kid like me at least – is the most ritualized, predictable, and institutionalized time of your life. Being a healthy child, with no economic or social deprivation and no visible, diagnosable or socially disturbing particularities, you just march, as fast as you can, towards deceptively clear futures. Thus, moving forward, you grow up developing a strong sensitivity to what common sensical ‘life’ looks like: when and how one should grow up and age, what maturation means, when to become independent, and how. As Richard Settersten (2003, 19) reminds:

Individuals use age-linked ‘mental maps’ to organize their own lives, the lives of others, and their general expectations about the life course. . . . These maps, in turn, serve important human needs for order and predictability.

It’s in the margins of our comfort zones, that we make, and thus find, otherness. Back then, for me, these margins featured Andre, who then appeared to me as a boy, dressed in man-like clothes (a pair of beige pants similar to my father’s, a checkered shirt buttoned all the way up, and brown, leather shoes). Andre was always in the company of his mother, Adèle, a small woman with medium grey hair, friendly looking, and always holding his hand. In many respects Andre and Adèle felt out of synch with my world: they were never in a hurry and they showed up at the school gates when no one was picking up or bringing children, when no one came back from work, to ‘just’ watch the children play. They did not ever seem to change, did not seem to have a future that differed much from the eternal present, nor did

they look properly ‘aged’ to me at that time. Quite a sensitive child, I must have asked my mother multiple times, “what is wrong with them?” Andre had Down syndrome: “It’s a pity, he’s a bit simple, yeah, I feel so sorry for her,” she used to add. At that moment, in a small village like mine, Down syndrome must have been one of the only recognized cognitive disabilities.



Figure 1: Family picture, 1973; from left to right: Sophie Sartain, Mimi Thornton, Bo Sartain, and Dona Thornton. Courtesy: Sophie Sartain

“Of course,” Settersten continues to argue, “lives as they are actually lived may deviate from cultural models of the life course” (2003, 19). Mimi and Dona, Adèle and Andre, Henriëtte, Willem and Kees,¹ and many others ask us—and our governments—to reconsider our expectations of the life course, to modify our age-linked ‘mental maps’ to include new realities, and to reconsider the diversity of relations between care, aging, and disability that exist and require support. It is to the wide affective resonance and the organizational complexities of aging with disability, in a kin-work and life course perspective, the documentary film, *Mimi and Dona* speaks.

Mimi and Dona (2014) is a coproduction of Independent Television Service (ITVS) and Corporation for Public Broadcasting (CPB), directed by Sophie Sartain.² It was nationally broadcast on PBS/Independent Lens and was screened on multiple film festivals, such as Dallas VideoFest, the ReelAbilities Festival, and the Thin Line Festival and is now available via Kanopy Streaming. The documentary gives an intimate portrait of a 92-year-old mother, Mimi, and her 64-year-old daughter, Dona, who has an intellectual disability, and the reverberations of their relationship in the lives and future imaginaries of a Texas family of which Sartain is part. Mimi and Dona’s lifeworld also echoes a relatively new phenomenon concerning aged adult caregivers of people with intellectual and developmental disabilities living to advanced age, while facing the lack of health care and social infrastructures to meet the challenges that come with this new reality.

In the US, in 2016, an estimate of 7.37 million people had some form of intellectual or developmental disability (IDD's) (Medisked and the The Arc 2018, 6).³ 70% of people with IDD live with a family caregiver, of which approximately 20% is 60 years or older (Medisked and The Arc 2018, 20). This caregiving situation is the consequence of decades of deinstitutionalisation and long waiting lists for specialized facilities, which are furthermore often too expensive for a large part of the caregivers, and/or have a bad reputation when it comes to quality of care. As both the person with IDD and the caregiver follow the general demographic trend of an increased life expectancy, this number is very likely to continue to grow: whereas people with IDD's used to have a life expectancy of 12 years in 1940, today, in Western countries, there is a median life expectancy of 65 years for women and 66 years for men (Forrester-Jones 2019, 10). People with intellectual and developmental disabilities are also more likely to develop comorbidities throughout their lives, such as Alzheimer's disease, which require more intense support. As a small-scale study in New Forest, South Hampshire (Forrester-Jones 2019) with 21 older caregivers (75 and over) of people with learning disabilities and autism shows, all older caregivers as well as some of their children face one inevitable, vital question: who will take care of my child/me in the future when I am/he or she is no longer able to?

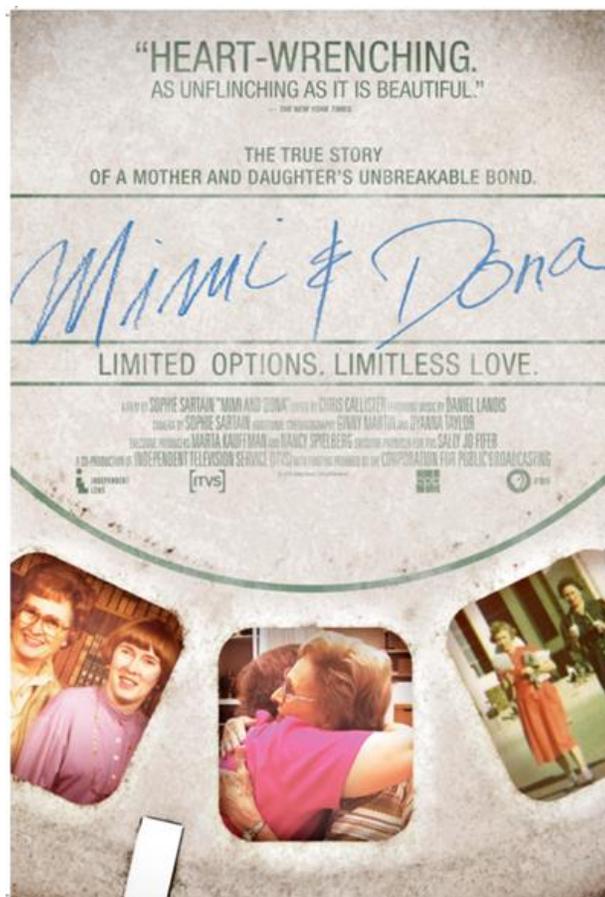


Figure 2: Poster for the film *Mimi and Dona*

Sophie Sartain witnesses the watershed moment, that was a long time coming, when Mimi nears the end of her caregiving abilities; when Mimi too, becomes 'disabled' to care. More than six years after the first screening of the documentary film, I invited filmmaker Sophie Sartain to pause on the origins and her motivations, on the making of, on the ethics of representation, and on the afterlives of this documentary.

“Please don’t taaake, my sunshiiiiine, away, waywayway waywayway.”

Christine Verbruggen: In 2008, when your father died from the effects of Multiple Sclerosis, you went back from Los Angeles to Dallas, Texas, to spend more time with your family, with the additional purpose of filming the ‘quirky’ life of your then 92-year-old grandmother Mimi and your 64-year-old aunt Dona. This coincided with the moment when Mimi had finally — after years of denial — given in to the fact that she was no longer able to care for Dona. You ended up documenting something that was on the verge of being lost. How would you sketch their daily lives up to that moment?

Sophie Sartain: Mimi and Dona had a very structured and insular life in their suburban home in Dallas. The house itself never seemed to change; it was like stepping into a time capsule from the 1960s. They didn’t seem to change either, with the exception of getting older. My grandfather died in 1968, so it was just the two of them for forty years.

Their life revolved around television programs and occasional outings, usually to nearby shopping malls, a few restaurants (mostly McDonald’s and Taco Bell), the supermarket, and the post office. Every Saturday at 1:00 pm, without fail, they went to a beauty salon to get their hair done. And every evening, Monday to Friday, they watched the game show, *Wheel of Fortune* at 6:30 pm. They would write down the answers to the puzzles on the show and keep track of how much money each contestant made. Many Sundays they went to services at a Methodist church in the neighborhood, though this became more infrequent as they got older.

Their main visitor was their friend Tony, an older man who had been Mimi’s ballroom dancing instructor when Mimi was in her 70s. In the 1990s, Mimi and Tony danced the waltz, tango, cha-cha, and rumba at senior showcases around Dallas. When I filmed the documentary, Tony was using Mimi’s converted garage as a dance studio to teach classes to senior citizens. Mimi and Dona loved seeing Tony when he came over, and we in the family liked it because he would check in on them.

CV: The documentary starts with the 92-year-old Mimi walking around the house with her back bent at a 90-degree angle, as if literally symbolizing the caregiver’s burden. The music in the background — “You are my sunshine, my only sunshine” — however more accurately evokes the atmosphere around the house and curbs these expectations. The recognition of a ‘caregiver’s burden’ is a relatively recent phenomenon, that might well have paralleled the deinstitutionalisation of care and is maybe more accurate to describe the burden of planning good care rather than everyday caregiving practices per se.⁴ Did Mimi ever speak of a burden of caring for Dona, and if she did, what was the main reason for that?

SS: Throughout her life, Mimi embraced caring for Dona and never expressed that it was a burden. Fiercely protective of Dona, Mimi seemed to know, deep in her bones, that she was the only one to care for her daughter. She did not want anyone interfering in their life, including her own family members. In addition, Mimi genuinely enjoyed being with Dona.

However, having said that, we did notice a change in Mimi around the time that I started filming. For the first time, at age 92, Mimi revealed that it was getting hard caring for Dona. Outings to the mall or the supermarket became challenging because Dona would wander off. Mimi, bent over with her walker, couldn’t keep up with Dona. One time at the mall, Mimi couldn’t find Dona, and a security guard had to retrieve her. Dona’s behavior also worsened — for instance, she shoplifted candy at the grocery store. When a manager caught her, he asked Mimi not to bring Dona back. We didn’t realize it at the time, but Dona was probably exhibiting the early signs of Alzheimer’s disease. So, she was changing, too, and for the first time, caring for her became a source of anxiety for Mimi.

CV: In a case study of a family caregiving situation involving a person with early-onset dementia, his wife, and his children, Silke Hoppe brings to the fore Marilyn Strathern's (1988) "dividuality" as a core concept to understand the mutuality, reciprocity, and systemics of caregiving assemblages (Hoppe 2020). In layman's terms, this would mean that Dona is part of Mimi, as much as Mimi is part of Dona. There are multiple moments in the documentary that represent this oft overlooked aspect of caregiving relations. The night before Dona will move out of the house is certainly one of the most telling moments in that regard. Mimi asks Dona, "you alright?" Dona answers, "yeah, I'm alright, mum. You alright?" The fact that this is moving, can, I think, also partly be explained by the fact that we are conditioned not to expect this kind of reciprocity in a caregiving relation. How does 'dividuality'—as a dynamic relational interiority—matter in the relation between Mimi and Dona and in the broader family system?

SS: In the film, my mom tells the story of her aunt who cared for a son with autism and cerebral palsy. When the son died, it was an unbearable loss for my mom's aunt. My mom remembers being haunted by her aunt's "deep moaning wail" at the funeral, as if a piece of herself had been brutally torn out. This speaks to the idea of "dividuality"—of mutuality and reciprocity in these family caregiving relationships.

In American culture and perhaps other cultures, the goal is for children to achieve independence—to leave the nest. That plays out in my own family. I have two brothers, and between the three of us, we live in California, Maryland, and Texas. We follow what many consider a successful model because we live independently thousands of miles apart. But is that the best model? What if your quality of life is better by not following this model? What if being a family caregiver brings purpose and meaning to your life? It's something I wanted to capture in the film—the fun Mimi and Dona had, the laughs, the quirky routines, and the shared experiences. After she was widowed at age 52, Mimi might have hoped to find a new romantic partner later in life or travel the world with friends. But Dona was a sweet companion, and they had a symbiotic relationship. Ultimately, for Mimi, it was not a burden but a joy.



Figure 3: Mimi and Dona at a birthday celebration. Courtesy: Sophie Sartain

CV: You use a powerful medium: (audio)visuals that allow you to show and tell the ongoing story of your aunt Dona and your grandmother Mimi. Penetrating the gaze like that, you do enter a terrain of vulnerability in multiple ways (e.g., the intimacy of family life, representations of disability, bodiliness, etc.). Both Dona and Mimi are, however, clearly aware of the camera and of your presence. One of the most magnificent examples is the evening before the transition when they do their evening ritual and say their prayers on the bedside for the camera. When forgetting the words, in a conspiracy-like manner, Mimi says to Dona: "Well, cover up your eyes, and we will do it like this, and she won't know we're not saying the lord's prayer," upon which Dona agrees: "Ok." How did the camera function for you, for them, and your family? What were the main ethical choices you made while making the documentary?

SS: At times Mimi and Dona seemed aware of the camera. Other times they forgot I was filming. They would go about their lives and chat with me as they normally would. As a documentary filmmaker, this is a dream come true; your subjects are completely themselves, not performing or editing themselves for the camera. It helped that it was just me in their home, not a crew and that I shot the film primarily with a small HD camcorder. Today, people can be even more unobtrusive with smartphones that take great video.

For me, the camera was both a magnet and a shield. It drew me to Dallas and made me show up. I was making a film after all. But the camera also allowed me to stay at a distance and suppress emotions. I toggled between being a family member and a filmmaker. The scene in which we left Dona at her new home was particularly gut-wrenching when Dona begged Mimi to take her home. The camera shielded me from the intense emotions of the moment. Later, when I watched the footage, I cried.

In terms of the ethical choices, those came later in the editing, when we had to decide what to include and what to leave out. There is a lot of talk in the documentary world right now about "extractive" filmmaking, the notion that we risk exploiting our subjects even if we have the best intentions. I welcome this conversation. We have to stay on top of this and constantly ask ourselves if what we are doing presents the truth in a way that uplifts our subjects and the issues they care about. This would not necessarily be the case in a film that exposes corruption or the actions of wrongdoers, but more in situations like Mimi and Dona's, in which vulnerable people trust us with their stories. To make the most powerful film, I wanted to show raw and intimate moments, but my hope is that they served the greater good of honoring Mimi and Dona's story and paying tribute to their incredible bond.

"I am too old to move there, I'm 64" (Dona to Sophie)

*"She almost knocked me down;
she wants to go around and count cracks in the house, all day long,
and that makes her mad when she can't do that."
(Mimi about Dona)*

*"I want you to be happy wherever you are."-"Like here?"
"Yeah, and anywhere else, if there's some other place,
if I'm not here, you can't live here by yourself."
(Mimi and Dona)*

CV: The first part of the film's subtitle is 'Limited Options.' How would you define the limitations in Mimi and Dona's younger life? And how did they persist or change when she and Dona grew older?

SS: As a child, Dona was asked to leave the public school system in Dallas. Though it was not easy for my grandparents financially, they found private schools for Dona to attend. My grandparents also had

to contend with the attitude in the 1950s that families would be better off sending children with disabilities to institutions. I don't think they ever considered this for Dona. Fortunately, our federal laws changed during the course of Dona's lifetime. Thanks to the dogged efforts of disability rights activists (captured in the wonderful documentary *Crip Camp* (2020) directed by our sound mixer Jim LeBrecht), all children in the US are now guaranteed a free and appropriate education. I wanted to highlight this change in policy to show that we can make progress and our government can mobilize to support families.



Figure 5: Dona and a classmate at a private school, circa 1960. Courtesy: Sophie Sartain

At the same time, we currently face a crisis in housing for aging Americans with disabilities. I wanted to spotlight this issue, too. In the film, when Mimi's difficulties in caring for Dona increase, my brother expresses frustration about the waitlists at community homes for people like my aunt Dona. He says, "three years, five years. We don't have five years. We might not even have five months." It was in this context that we had to act quickly to find a home for Dona.

CV: What did it actually mean for Mimi not to be able to care for Dona anymore?

SS: As Mimi and Dona aged, their world became smaller. They left the house less frequently because, as mentioned, Mimi had a harder time keeping track of Dona in public. She couldn't keep up with her if Dona left her side. This was a change. The film shows that Dona's behavior also changed at home. Dona always had her interests, bordering on obsessions, such as writing down license plate numbers and serial numbers on dollar bills. These obsessions intensified over the years. Mimi complained that Dona would pace around the house and count cracks in the ceilings of the rooms. When Mimi tried to

stop Dona from counting cracks, Mimi said that Dona pushed her and “almost knocked me down.” At age 92, Mimi was stubbornly independent, but she had become weaker, her hearing had diminished, and she probably shouldn’t have been driving. These developments pointed to her not being able to care for Dona, and then the kicker was Mimi’s own admission that she didn’t think she could do it anymore.

CV: When getting back in the car, after bringing Dona to Denton State School, both Mimi and Dona have a very hard time, with Dona becoming angry, sad, and therefore aggressive and with Mimi ready to get out of the car to take Dona back home. At that point, she screams: “Y’all made me do this!!” It’s them against the rest, at that point. Yet, among family members, there are quite some divergent opinions about what Mimi should do or should have done with Dona and about Dona as a person. Can you frame those different opinions?

SS: We had different opinions about what might be best for Dona, and I’m grateful that my family allowed me to show all sides of the debate—especially when it didn’t paint us in the best light. One of my brothers expressed criticism with Mimi for not enabling Dona to be more independent. His beliefs echoed those of my father, who felt that Mimi should have moved Dona to a community home earlier in life. Another brother, who has a son on the autism spectrum, voiced more ambivalence and understanding as someone in a situation like Mimi’s. “I sometimes feel I have to live forever and outlive him,” my brother said of his son, who is now in his 20s and living at home. My mom’s cousin Betty thought Dona might be happy living with her in a more rural setting in East Texas, but Betty had some health setbacks making this impossible. I wondered if we could find 24-hour care for Mimi and Dona in their home—an expensive option but possible, at least for a while. However, on the few occasions when we tried to bring in people, Mimi became agitated and suspicious and demanded that the person leave. She hated having outsiders in her home. My mom (Mimi’s daughter and Dona’s sister) found herself in the middle of this. “Trying to figure out what to do with someone like Dona is very difficult,” she said. “There’s not a formula that fits everybody.”



Figure 5: Keith Sartain and his son William. Courtesy: Sophie Sartain

Ultimately, our opinions were only that—opinions—because we had to follow what Mimi wanted. The minister at her church had recommended the Denton State School, a state-run institution, as a place she should consider for Dona. He told her that another family at the church had a family member there and they were happy. This had a big influence on Mimi, bigger perhaps than what her family members said. In the end, she made the decision to send Dona to the Denton State School in 2009.

CV: There is a strong thread about institutional care with little or no critique to its potential failures, which contrast sharply with the public and academic debate on institutional care. Was this deliberate?

SS: We had reservations about a state-run institution given the media coverage we had seen in recent decades, dating back to Geraldo Rivera's shocking exposé of the Willowbrook State School in New York in 1972. The Denton State School did not seem ideal to us. And yet, we found ourselves surprised when we toured the facility. It was on a big campus and offered a menu of activities and what seemed like a good ratio of residents to staff members. We really liked the case manager and the team assigned to Dona. And again, this was Mimi's decision. Knowing this, we may have engaged in some wishful thinking about how Dona would do there. We also, at that point, did not know that Dona might be in the early stages of Alzheimer's disease. We missed the signs. As far as the film goes, we had a longer section on the controversial history of these institutions, including reports of horrifying conditions and instances of abuse, but we ended up trimming this section for time and to keep the focus on Mimi and Dona.



Figure 6: Dona and Mimi in front of their house in Dallas, Texas. Courtesy: Sophie Sartain

CV: The protagonists in the film are deepened and narrativized in their complexity: e.g., your mother (also for you) becomes a sibling that has a hard time living with a sister like Dona and moves out of the house; Mimi becomes a woman who makes her own dresses and likes dancing. Dona, however, apart from transitioning and adjusting to institutional life and dramatically changing through Alzheimer's disease, stays rather flat and static. It's only your mother Merrily's cousin Betty who says:

I felt really sad for Dona. How did Dona feel when she was left in there? That's what tore me up, Sophie. We never knew what Dona was thinking or feeling as she got older. And when she was little—when she was playing with the doodle bugs and the wasp and these kind of things.

Did this resonate with your feelings about 'voicing' Dona's feelings and inner world?

SS: I love it when Betty makes this observation. It is emblematic of the grappling we all did around the decision to move Dona and the results of that move. Dona was often hard to read, especially as she got older. And from the time I was a child and first remember Dona until I started making the film, she did seem unchanged to me. She talked about the same things in 2010 that she talked about in the 1970s – for instance, about the time she saw The Beatles in concert and about old boyfriends (real and imagined) and how she wanted me to be the flower girl in her wedding. Things like that. Looking back now, I realize that I did ask Dona everything I wanted to ask her. The problem is that I didn't listen to her. When I asked her if she wanted to move to Denton, she said no. When I said, why not, she said, "I'm 64. I'm too old to go there." Now I see that, even though none of us could have predicted the outcome, Dona was probably right. I wish I had listened to her better. I am still grappling with this.

The afterlife

*"Everybody wanted me to do it, but they don't know what it is to give up somebody. I know what it is to give up Ozzy when he died. But to give up a young woman like Dona."
(Mimi the day after the move to Denton State School)*

The first couple of months after the move to Denton State School, things seem to go pretty well for Dona, and it's Mimi who seems to suffer most from the separation. When Sophie comes to visit her, the day after Mimi came to see her after her first month home alone, she seems to be integrating quite well, pointing to her picture on the wall in the facility, as if to say: 'this is where I live.' When Mimi calls, she doesn't really want to talk too long. However, after Mimi's 93rd birthday, things get worse: Dona refuses to eat, is more and more aggressive, and her situation worsens, both physically and mentally. As mentioned earlier, Dona seems to have developed Alzheimer's disease, which is common for people with IDD's. The case manager says that the symptoms might have worsened through the dramatic change of moving into the institution and that it otherwise would have happened anyway.



Figure 7: Mimi and Dona after Dona's move to the Denton State School. Courtesy: Sophie Sartain.

She has also developed a urinary infection which doesn't improve. Not knowing what to do, they take her home (for a while), hoping that she would feel better and regain some strength. One month later, after the short trip home, she ends up at the emergency room where, miraculously, as her urinary infection is treated, after two weeks, Dona is both physically and mentally recovering. Sophie's mother, Merrily, is relieved: "So now we can hope again." But the hope is short-lived, and the help for Dona is limited to visits and shared moments at birthday parties until she dies in her sleep, at age 70, in January 2015. Sartain's work bears witness to the fact that Dona has left a strong imprint on the lives of those who outlive her.

CV: How, in general, did living with Dona in your earlier years, as part of the family, change your feel for diversity in your later life? And how, maybe, did this approach change while making the documentary and through the diagnosis of your son Ben?

SS: It was a gift growing up with Dona. As a child, I spent weekends at her house. She and I would catch fireflies and chameleons in the backyard and put them in mason jars. We'd place the chameleons on the green felt pool table they had and watch the chameleons change from brown to green. It was magical to a 5-year-old. Dona was so fun. She was my aunt and also my playmate. As I got older, I became confused about Dona. I thought that grown-ups were supposed to have jobs and maybe get married and have families. One day when I was about 8 or 9-years-old, I blurted out in frustration to my mom, "Dona's dumb." My mom corrected me and explained about Dona. It was enriching for me to learn about differences and understand that we're not all alike. I also benefited from meeting Dona's friends. Her best friend Margie came to the house a lot. Margie was a hoot and mischievous like Dona. She and Dona were my version of Lucy and Ethel, always scheming and getting into trouble.



Figure 8: Dona Thornton in her 20's, playing music. "She was my aunt and also my playmate." Courtesy: Sophie Sartain.

With my son, who received an autism diagnosis in the middle of making the film, the situation was different—mainly because he's his own person with his own strengths and challenges (like all of us) and because our world has evolved in its understanding of diversity and autism. One way my

experience with Dona may have informed the situation with my son was in his early diagnosis. Knowing that we had autism in the family, I was on the lookout for any signs and didn't hesitate to get evaluations. My son is now a teenager and in a great school and surrounded by friends who are proudly "autismic" (their term). The other day, he saw a picture of himself at age 12 and joked, "There's a kid who's about to lecture you on the inner workings of a steam engine." We couldn't stop laughing.

CV: There is indeed a ripple effect of 'autism' in your family throughout three generations. The documentary, instead of dramatizing hereditariness, focuses instead on lessons to be learned on the sharing of intergenerational knowledge. The most powerful lesson in this regard—and the second subtitle—is 'Limitless love.' Also, in the follow up documentary, Sophie and Ben, you witness: "What Mimi taught me was unconditional love." Do you see intergenerational differences in your family concerning the realization of this love, and, for example, the uneasy relation to (in)dependence and self-realisation? What lessons would you teach your kids when struggling to integrate intergenerational knowledge in contemporary conditions?

SS: Oh my, you ask good questions! We can be so hard on the generations before us, second-guessing their decisions when it's almost impossible to understand their circumstances. If, for instance, I had had doctors, teachers, and admired religious figures telling me in the 1950s that I should send a child with IDD to an institution, would I have been tempted to follow that advice? I don't know how I would have reacted. I believe our understanding of the brain will expand exponentially in the years to come and that future generations will shake their heads at how clueless we were. I hope this happens because it would signify progress. But I also hope that future generations temper their judgment with compassion. We are doing our best with the information we have. Mimi is a role model for me because, aside from her time-bound circumstances, she embodied something timeless. She was strong, fierce, and rock-solid in her love. I hope I can pass something like that along to my children and grandchildren. At the end of the day, what is more important than that?

CV: The film was nationally broadcasted on PBS/Independent Lens. This surely boosted its public visibility. Speaking on the convergence of intellectual and developmental disabilities, aging, care, (de)institutionalisation, family histories . . . you have a lot of potential audiences. Who are your audiences (e.g., caregivers of people with IDD; schools; nursing homes; disability scholars; gerontologists; policymakers; classrooms; asf.)? How different was the documentary appreciated by e.g., activists for people with IDD's or activists in the field of neurodiversity and professional caregivers or educators?

SS: Although I started out making a small and personal film about my family, I quickly realized that I had tapped into something much bigger. More often than not, when I would tell someone about Mimi and Dona's situation, they would chime in that they knew someone in the same predicament—a cousin, a neighbor, or a friend's sibling, some with developmental disabilities, others with mental illnesses, all struggling to find appropriate care and housing for a loved one. I realized that this was an untold story happening all around us, with caregivers like my grandmother facing agonizing decisions, often with little support or guidance.

An early ally and advisor on the film was Don Meyer, founder of the Sibling Support Project. He identified with my mom, who grew up with unique challenges as Dona's sister. I also received guidance and support from experts in autism and advocates for people with IDD. Through film festival screenings, community screenings, and the PBS broadcast, the documentary reached millions of viewers, something I couldn't have fathomed when I first took my camera to Dallas in 2009. I heard moving stories from viewers all over the US who had family situations like mine. It was incredibly gratifying.

Once I made the film available to schools and institutions through New Day Films, I reached new audiences in academic fields and the caregiving world. One professor of a developmental disabilities class at Oklahoma State University assigned the film to her students. Amazingly, many of them wrote me thank-you notes after watching it. The film screened through state agencies such as the Pennsylvania Department of Health's Bureau of Family Health, which held nine community screenings for families and caregivers around the state. *Mimi and Dona* also screened at conferences such as the American Society on Aging (ASA) Conference, where I met gerontologists, social workers, and clinicians who've since used the film for training purposes. I'm heartened that it continues to be viewed and used as a teaching tool six years after its broadcast.



Figure 9: Notes from students at Oklahoma State University who watched the film in a class. Courtesy: Sophie Sartain.

CV: As we speak, you have an audience of researchers and practitioners of a wide variety of disciplines (gerontologists, anthropologists, disability scholars, nurses, social workers, architects, ...) ready to run off and see the documentary. Thinking about your experiences with *Mimi and Dona*, what would you want them to focus on concerning aging into disability/disability into aging?

SS: First of all, I want to thank them for their work and for devoting their research and talents to areas that are often overlooked in our society. Obviously, as our population ages and people with disabilities live longer, the complex issues of finding care and safe and affordable housing for these vulnerable populations will only grow.

In terms of an area of focus, I would love to see more research and data about the benefits of caregiving in addition to the important work being done to document its burdens. I'm a storyteller, so it's beyond me to know if caregiving has measurable benefits, but in my own family, I have seen some positive aspects. My mom was the primary caregiver for my dad in his final years, before he died from Multiple Sclerosis at age 65. Although it was incredibly difficult and heartbreaking to witness his decline, she also told me that it was the closest they ever were in their 42-year marriage. And Mimi lived to be 100. It may have been a combination of genes, luck, economic security, and access to good health care. But her life also had purpose and meaning as Dona's caregiver, and this might have contributed to her longevity. Not to mention companionship—the idea of “dividuality” that you brought up. Mimi and Dona had many laughs just sitting in their favorite chairs every night, trying to guess the phrases on their favorite game show, *Wheel of Fortune*. It might not have been as exciting as traveling the world, but for them, it was a lovely way to spend an evening.



Figure 10: Mimi Thornton turning 100: “her life also had purpose and meaning as Dona’s caregiver, and this might have contributed to her longevity.” Courtesy: Sophie Sartain

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Notes

1. Kees Momma (born in 1965) is a remarkable, witty, and intelligent Dutch man on the autism spectrum, who lives in a chalet in the garden with his 80+ parents, Henriëtte and Willem. Director Monique Nolte first documented Kees’ and his family’s life in *Trainman* (1998), and in 2014 released the award-winning follow up, *Het Beste voor Kees* [What’s Best for Kees]. The last documentary film especially focuses on the question central to *Mimi and Dona*: who will take care of Kees when Henriëtte and Willem are no longer able to, and what *is* best for Kees? Both

documentary films have served to raise awareness on neurodiversity in the Netherlands and keeps attracting a lot of public attention. Nolte is now working on the third production with Kees Momma, *Kees Vliegt Uit* [Kees Leaves the Nest], documenting Kees' steps towards another episode in his life of supported in(ter)dependence.

2. Sophie Sartain's other credits include *Seeing Allred* (2018, co-director and producer), *Above and Beyond* (2014, writer), *Hava Nagila (The Movie)* (2012, producer and writer); and *Blessed Is the Match: The Life and Death of Hannah Senesh* (2008, writer and co-producer).

3. The definition of intellectual and developmental disability used in the Discussion Guide of Mimi and Dona is:

Intellectual disability (also known as "intellectual disorder") is characterized by deficits in general mental abilities, such as reasoning, problem solving, planning, abstract thinking, judgment, academic learning, and learning from experience. The deficits result in impairments of adaptive functioning, such that the individual fails to meet standards of personal independence and social responsibility in one or more aspects of daily life, including communication, social participation, academic or occupational functioning, and personal independence at home or in community settings. (Discussion Guide 6)

4. For a critical appraisal of the 'caregiver's burden,' see Warren, Narelle, and Dikaios Sakkeliariou. 2020. "Neurodegeneration and the Intersubjectivities of Care." *Medical Anthropology* 39 (1): 1-15, DOI: 10.1080/01459740.2019.1570189.

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