



Mimi and Dona by Sophie Sartain

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BI FILM-VIDEO REVIEW

Mimi and Dona by Sophie Sartain (2015)

“...And when we’re gone, long gone
The only thing that will have mattered
Is the love that we shared
And the way that we cared...”
(Kieran Kane & Paul O’Hara)

In the closing scene of Sophie Sartain’s documentary, *Mimi and Dona*, these lyrics invite the viewer to reflect on what matters most as people with intellectual and developmental disabilities (IDDs) and their caregivers age and reach end-of-life. This intimate documentary is both poignant and timely, given the unprecedented growth of people with IDD living to advanced age. In 2000, there were approximately 640,000 people with IDD who were 60 years or older living in the United States; this number is projected to double by 2030 as a result of advances in health care (Hahn, Fox, & Janicki, 2015). People with IDD now have mortality and morbidity patterns very similar to the general population; however, they are frequently aging with complex comorbidities and unique behavioral and psychiatric needs (Tuffrey-Wijne & McLaughlin, 2015). Seventy-five percent of people with IDD live with a family caregiver, 25% of whom are over 60 years old. Yet, only 5% of funding for IDD services is directed to family support, and extensive waitlists for services often leave aging families with limited support and difficult decisions (Heller, Stafford, Davis, Sedlezky, & Gaylord, 2010).

Social workers have been identified as “linchpins” because of the critical role they play in assuring that the social and health needs of older adults with IDD and their caregivers are met (Robinson, Dauenhauer, Bishop, & Baxter, 2012). The need for BSW and MSW coursework to be more inclusive of IDD-specific content, including opportunities for exposure to the lived experiences of older adults with IDD and their caregivers, has been identified (Kropf, 1996; Parish & Lutwick, 2005). *Mimi and Dona* was screened and reviewed by a class of MSW students. Student feedback illustrates the documentary’s objectives and implications for education and practice.

Mimi and Dona is a deeply personal story about the last 5 years of Dona’s life. When the film begins, Dona—who has a diagnosed intellectual disability—is 64 years old and living at home with her 92-year-old mother, Mimi. Sartain is Mimi’s granddaughter and Dona’s niece, which gives her—and the viewer—access to private, emotional, and difficult moments that frequently occur in the lives of older adults with IDD and their caregivers but are rarely documented. One student commented, “This film was incredibly touching but also a challenging glimpse into the struggles of an aging family, particularly of two women who rely deeply upon one another.” This film provides a bravely honest depiction of the heart-wrenching transition that this family experienced. Viewers observe how lifelong caregiving may not be feasible for parents of adult children with IDD, especially as they begin to experience their own chronic illness and disability together with increasing physical, social, and emotional needs in their aging children. The implications of the intersection of aging and IDD are laid bare in the documentary. Viewers observe the limited number of high-quality options available to families, the

difficult choices that must be made when out-of-home care becomes necessary, and the physical and emotional manifestations of relocation stress.

The documentary explores aging with an IDD in the context of historical, present-day, and future policies and practices. A student reflected, “The film examines the realities of a somewhat fragmented system of services for people with IDD in America.” Photos, documents, and commentary help the viewer to understand how services for people with IDD were extremely limited and early out-of-home placement was once considered a best practice. The documentary highlights how investigative journalism and advocacy campaigns led to the deinstitutionalization movement; yet, services have failed to keep pace and waitlists have proliferated in the wake of the trend toward community-based care. Sartain also presents the story of her own family as they adjust to the diagnosis of her son with an autism spectrum disorder (ASD) and a cousin who describes his experiences caring for a teenage son with ASD. While both acknowledge that many more services are available to their children when compared to Dona, their concerns parallel those expressed by Mimi throughout the film. Sartain’s cousin reflects, “I just pretty much have to live forever and outlive him.”

Mimi and Dona illustrates the lifelong implications of IDD on the entire family system. One student commented, “Through interviews and artifacts, the film did a fascinating job of showing family dynamics and how family history impacts an individual throughout life.” Sartain interviews her grandmother, mother, aunts and uncles, and cousins who candidly describe their experiences with Dona, which as one student noted “is a side of the story that is often untold.” Sartain’s mother Merrily lived a difficult adolescence as Dona’s sister and it became a catalyst for leaving home to marry someone she barely knew. Following the dissolution of her first marriage, the documentary illustrates how the long-term stress of caregiving fractured her second marriage and led to disagreements about the responsibility for Dona’s care after her father’s death. Competing beliefs about where, when, and how Dona should transition to a residential placement leave the viewer wondering who can and should have a voice in the lives of people with IDD.

Sartain and her family invite the viewer into intimate and personal moments over an extended period of time in a way that texts, case studies, and other films exploring aging with an IDD have not. As one student noted, “The film allows the audience to have a rare and somewhat raw opportunity to step inside the world of a family who is living and interacting with an aging adult who has an IDD.” MSW students commented that the film facilitated a deeper understanding of and empathy for the unique challenges faced by people with IDD and their aging caregivers. A student noted, “...Watching this film allowed me to connect information presented in the classroom and readings with the actual experiences of people like Mimi and Dona.” The film, by highlighting the limitations of current service systems, also prompts students to consider how social workers can advocate for improved transition planning, additional family support, and decreased waitlists.

Mimi and Dona is a powerful and important film for students, practitioners, educators, and policymakers who are interested in older adults with IDD. One student astutely commented that the issues presented are not “disability specific” but rather the documentary takes an unflinching, long look at caregiving in the United States. *Mimi and Dona* can be a springboard for facilitating meaningful conversations with social work students about practice and policy. To close with a student reflection,

Being able to get a first-hand look “behind the scenes” of what it is like to live with and take care of someone with an IDD was invaluable to me as a student. It is one thing to learn

about IDD and see someone with a particular disability in the clinic, but to see their intimate home-life puts everything into context.

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