

# DISCUSSION GUIDE



Mimi & Dona

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# Using This Guide

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This discussion guide is designed as a tool to facilitate dialogue, and deepen understanding of the complex issues in the film *MIMI AND DONA*. It is also an invitation to not only sit back and watch the show—but to step up and take action.

This guide is not meant to be a comprehensive primer on a given topic. Rather, it provides important context, and raises thought-provoking questions to encourage viewers to think more deeply. We provide suggestions for areas to explore in panel discussions, in the classroom, in other community settings, and online. We also provide valuable resources, and connections to organizations on the ground that are fighting to make a difference support families like the one profiled in the film.



[Visit the MIMI AND DONA website for more information.](#)



Filmmaker Sophie Sartain

“I grew as a parent to my own children by witnessing the awe-inspiring love Mimi gave Dona her entire life.”

MIMI AND DONA is a personal documentary about my aunt and grandmother. I set out to make it in 2009, taking a small HDV camera from Los Angeles to Dallas to capture the sweet and quirky world of my grandmother Mimi and my aunt Dona. Time was scarce. At 92, Mimi had finally admitted that she could no longer care for her daughter Dona, who has an intellectual disability; and my mother (Dona’s sister) had submitted an application to move Dona to a state-run institution in Denton, Texas. After 64 years, Mimi would have an empty nest, and Dona would suddenly be on her own, without her mother’s constant presence.

Over the course of the summer, I filmed Mimi and Dona’s bickering and tenderness, their jaunts to the beauty parlor and McDonalds, and their near religious obsession with *Wheel of Fortune*. I also interviewed my mother and my brother, who voiced the ambivalence we were all feeling. Was this the right thing for Dona? Would Mimi fall apart without her?

Back in Los Angeles, whenever I told people 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. This was an untold story happening all around us, with caregivers like my grandmother facing agonizing decisions, often with little support or guidance.

# From the Filmmaker

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Over the next six years, I flew to Dallas eighteen times to document Mimi and Dona’s story. I gained new understanding and admiration of my mother as the sibling of person with a disability; she represents countless brothers and sisters who overcome difficult childhoods and then assume the responsibility of caring for their adult siblings. I made discoveries about my childhood—why there was unspoken tension in the family and how it could be traced back to an unfortunate misunderstanding about my aunt Dona. I also grew as a parent to my own children—in particular to my son who is on the autism spectrum—by witnessing the awe-inspiring love Mimi gave Dona her entire life.

Now that MIMI AND DONA is finished, I believe we are on the cusp of a crisis with our aging population of people with intellectual and developmental disabilities. Through the story of MIMI AND DONA, I hope to illuminate a pressing social issue—finding appropriate housing and support for this vulnerable population—and foster greater respect and compassion for the families and caregivers of people with disabilities.



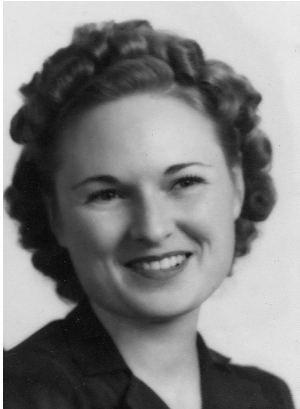
## PRODUCTION NOTES:

Film was shot in Dallas and Los Angeles over a six-year span.

Most challenging shooting location was Dona’s new home at the state-run institution.

Film was primarily shot with a handheld HDV camera, the Canon VIXIA, and edited with Final Cut Pro 7.

72 hours of original footage was edited to create the final hour-long film.



• An estimated 4.6 million Americans have an intellectual or developmental disability (I/DD).

• These individuals are living longer than ever before. And more than 75% of them live at home with family. What happens when aging family members can no longer care for them? What are the options for this vulnerable population? How can we better support them and their families? MIMI AND DONA raises these questions through the story of a deeply connected mother-daughter duo.



• Since her husband died in 1968, Mimi Thornton has lived with her daughter Dona in a suburban home in Dallas. Dona has an intellectual disability that affects her ability to process information, plan and problem solve, and interact socially. Over the years, Mimi and Dona have carved out a happy life for themselves—one filled with errands, church, weekly visits to the beauty parlor and nightly doses of *Wheel of Fortune*.

• Frozen in time, they have lived off their Social Security checks, inside the same four walls, for forty years. However, Mimi and Dona's symbiotic existence is about to end. At age 92, Mimi can no longer care for Dona; and at age 64, Dona is about to take the biggest step of her life. She's leaving home to live in a state-run institution.

• Filmmaker Sophie Sartain is Mimi's granddaughter and Dona's niece. In this personal documentary, she chronicles the heart-wrenching process of separating her aunt and grandmother. Sophie also reaches back to explore the complicated legacy of Dona's disability on three generations of her Texas family.

# Background Information

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## What is an intellectual disability?

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.

## What is a developmental disability?

The current definition under the Developmental Disabilities Act (DD Act), adopted in 2000, defines “developmental disability” as a severe, chronic disability of an individual that:

“is attributable to a mental or physical impairment or combination of mental and physical impairments; is manifested before the individual attains age 22; is likely to continue indefinitely; results in substantial functional limitations in 3 or more of the following areas of major life activity: self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, economic self-sufficiency; and reflects the individual’s need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated.”

## INTELLECTUAL AND DEVELOPMENTAL DISABILITY (I/DD)

Source:

[http://www.acl.gov/Programs/AIDD/DD\\_History/index.aspx](http://www.acl.gov/Programs/AIDD/DD_History/index.aspx)

# Background Information

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## FACTS AND FIGURES ON OLDER ADULTS WITH I/DD

- An estimated 4.6 million Americans have an intellectual or developmental disability. (*The ARC, 2000*)
- Of these 4.6 million, an estimated 75% live at home with family members caring for them and more than 25% of family care providers are over the age of 60 years. (*Tamar Heller, University of Minnesota, 2010*)
- Nationally, more than 322,000 people are on waiting lists for Home and Community Based Services. (*United Cerebral Palsy, 2015*)
- Historically, people with intellectual disabilities did not live as long as the general population and were at increased risk for health problems. Also, until recently, it was common for people with intellectual disabilities to be institutionalized, and treatments were either nonexistent, ineffective, or harmful. (*NIH Fact Sheet, 2010*)
- Today, people with developmental disabilities are living longer, due to medical advances and better, earlier treatments and services, and are aging at unprecedented rates, with unique health and service needs. (*University of Illinois at Chicago, 2010*)
- Some adults with intellectual disorders are also at a high risk for developing dementia; and recent research shows that 75% of individuals with Down syndrome who live past age 65 will be diagnosed with Alzheimer's disease. ([UCLA, 2015](#))



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Throughout history, societies have ostracized and marginalized those who had disabilities. Our standard language often reflects this sort of discriminatory thinking. The ancient Greeks and Romans felt that children with intellectual disabilities were born because the gods had been angered. Often children with severe intellectual disabilities would be allowed to die of exposure during infancy rather than being permitted to grow up. (*Parnel Wickham, 2010*)

In modern times, a variety of terms have been used to describe intellectual disability. The introduction of the IQ test in the United States in 1916 was followed by a classification system that used such terms as “moron” (IQ of 51–70), “imbecile” (26–50), and “idiot” (0–25). By the 1960s, “mental retardation” was the preferred medical term, gradually replacing those previous diagnostic terms that had come to carry pejorative connotations.

Today, the term “mental retardation” is widely regarded as outdated and offensive. In 2010, President Obama signed [Rosa’s Law](#), which removes the terms “mental retardation” and “mentally retarded” from all federal health, education and labor policy documents. Instead, “people first” language is used that refers to the person first, and the disability second, such as saying “individuals with an intellectual disability.” Most states have followed that practice, but popular culture has lagged behind, even with the best efforts of the Special Olympics initiative with their “[spread the word to stop the word](#)” against using the word “retarded” which they refer to as the “r-word.”



## CHANGING LANGUAGE AND EVOLVING ATTITUDES

# Background Information

## A HISTORY OF CAREGIVING OF PEOPLE WITH I/DD



• For centuries, families took care of their children with all types of disabilities at home, often with help from extended family members. Since most families lived in rural communities, some people with intellectual disabilities were able to physically help out with farm-related jobs. This changed around the turn of the 20th century. Urbanization took hold, and employment increasingly depended on intellectual rather than physical ability. This time period also witnessed the rise of the eugenics movement, which concluded that genetics were the main driver of intellect, criminality and physical fitness. (*History of Intellectual Disability, 2010*)

• Beginning in the late 1800s and early 1900s, individuals with intellectual and developmental disabilities were segregated into institutional settings so as to protect “normal” society from them and to control their reproductive lives, often by forced sterilization. Parents were often counseled by doctors to institutionalize their young children “for the sake of your marriage” or “for your other children.” (*Family Voices, 2012*)

• In each state, people with mental illness or intellectual disabilities were placed in institutions, the largest of which housed as many as 20,000 people. Living conditions could be horrible: in one Pennsylvania facility, it was common for more than 100 people to share a single bedroom. Facilities were often filthy, with excrement and urine on the floors and walls. (*Keystone Human Services, 2015*)

• After World War II, activism of parents on the behalf of their physically and mentally disabled children arose. A movement towards deinstitutionalization followed. In 1975 Congress enacted a guarantee of free public education to children with disabilities by passing the Education for All Handicapped Children Act, later renamed the Individuals with Disabilities Education Act (IDEA). As a result, schools had an obligation

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to provide educational and training services for school-age children. There was also a trend for community-based group homes to replace state institutions. (*Disability Rights Education and Defense Fund, 1992*)

Today, parents are typically the primary caregivers of their children with intellectual disabilities. This extends into adulthood, as the majority of people with intellectual disabilities still live with parents or other relatives past the age of 22. (*The ARC: Out of the Shadows, 2011*)

In 2014, new federal Medicaid rules were enacted that require states to provide more community-based services for adults with intellectual and developmental disabilities such as autism. These rules are meant to increase access to the benefits of community living (as opposed to institutional living). Their aim is also to ensure that Medicaid funding and policy support states in their efforts to meet their obligations under the Americans with Disabilities Act (ADA). (*The ARC, 2014*)

Today there is a growing self-advocacy movement of adults with intellectual and developmental disabilities, saying that services and programs must be developed and implemented with their input. (*Autistic Self-Advocacy Network, 2015*)



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## AMERICANS WITH DISABILITIES ACT— BEFORE AND AFTER

The ADA prohibits discrimination against individuals with disabilities in all areas of public life, including jobs, schools, transportation, and all public and private places that are open to the general public. To be protected by the ADA, one must have a disability, which is defined by the ADA as a physical or mental impairment that substantially limits one or more major life activities, a person who has a history or record of such impairment, or a person who is perceived by others as having such an impairment.

• The 25th anniversary of the American with Disabilities Act (ADA) was celebrated on July 26, 2015, and it is easy to forget what life was like for people with disabilities before it existed. Public buildings, parks and schools were often inaccessible for people who used wheelchairs or walkers, with no required elevators or ramps. Even getting around an airport and onto a plane was difficult, if not impossible. As a result, people with disabilities were often stuck at home, out of sight and out of mind.

• Before the ADA, private-sector discrimination against people with disabilities was legal, absent a federal grant or contract. Employees could be fired for treating their disability, such as someone with diabetes needing a break to check glucose levels and administer an insulin injection. People with disabilities faced housing discrimination as well.

• In 1988, Senator Tom Harkin (D-IA) authored and sponsored what became the Americans with Disabilities Act. Harkin delivered part of his introductory speech to Congress in sign language, saying it was so his deaf brother could understand. Critics, including many in the business community, feared that the proposed legislation would be too costly. The U.S. Chamber of Commerce lobbied against it, saying its passage would have “a disastrous impact on many small businesses struggling to survive.” However, with bi-partisan support, the ADA passed Congress and was signed into law in 1990 by President George H.W. Bush. For more info, please visit <http://www.ada.gov/>.

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Despite the many gains, there is still uncertainty about federal support for people with disabilities, including maintenance of Medicaid and Social Security Disability Insurance (SSDI), which provides income to certain individuals who are unable to work due to their disability. Congress must act by Dec. 21, 2016, to prevent a 20% across-the-board cut in SSDI.

On the special education front, a bi-partisan bill called the IDEA Full Funding Act has been introduced to put an end to the underfunding of special education. Over time, this bill would fulfill the pledge Congress made in 1975 to cover 40% of the average cost to educate children with disabilities. ([senate.gov](http://senate.gov), 2014)

In the 40 years since the passage of the Individuals with Disabilities Education Act (IDEA), which guaranteed a free, appropriate public education to each child with a disability in every state and locality across the country, the federal government share of special education has been below the law's 40% mandate. Currently the federal share is around 15.8% of all enrolled students. As a result, costs have been shifted to the states, forcing school districts to raise taxes or dip into general education budgets and cut other critical services to make up for the shortfall. (*Council for Exceptional Children, 2015*)

## CURRENT DISABILITY-RELATED LEGISLATION



## HELP ADDRESS HOUSING SHORTAGES FOR PEOPLE WITH I/DD

1. Educate policymakers to provide sufficient funding for all housing vouchers that are currently issued or leased, and restore the program to pre-sequestration levels.

2. Help homeowner families donate their homes to nonprofit housing foundations so that their son or daughter can live in the house for the rest of his or her life.

3. Increase employment opportunities for people with disabilities to help close the affordability gap and, by minimizing the amount of rental assistance needed to afford housing, stretch limited rental resources farther.

For more info, please visit [the.arc.org](http://the.arc.org)

## HOUSING SHORTAGES FOR PEOPLE WITH I/DD

Across the United States, people with intellectual and developmental disabilities (I/DD) face a severe housing crisis. First, there is the issue of affordability, as many adults with I/DD must live on Supplemental Security Income (SSI), which provides an average monthly payment of \$559 for people ages 19-64. With such low monthly payments, people with disabilities are priced out of most rental housing markets. Government programs that provide subsidized housing—meaning a subsidy that helps renters pay no more than 30% of their income for housing—such as Section 8 vouchers, are underfunded and often have long waiting lists. (*The ARC, Housing Issues for People with Disabilities, 2015*)

There's also the problem of physical accessibility, as many apartment units have doorways that are too narrow, no elevators, and lack other accessibility features such as lowered kitchen counters and wheel-in showers for people who use wheelchairs. Unfortunately, there's also discrimination in the private housing market. Although federal laws prohibit discrimination in public and privately funded housing, a majority of complaints received by HUD's Fair Housing Enforcement Office are from people with disabilities. (*The ARC, Civil Rights Issues, 2015*)

In the next decade, this housing crisis is expected to deepen, since over 850,000 people nationally with I/DD live with an aging family caregiver over age 60. As those aging parents become ill, frail or pass away, their adult children are at risk of losing their homes and can be subject to institutionalization or homelessness due to the shortage of housing and support services.

## Share the film.

Arrange for a screening of MIMI AND DONA at a community-service, faith-based or special needs organization in your area. [Contact us to schedule a screening of MIMI AND DONA.](#)

## Volunteer with a Friendly Visitor program.

These programs match volunteers with seniors for weekly visits, nurturing long-lasting friendships by bringing generations together to share ideas, mutual interests, and experiences. They often operate out of local senior centers and other local family service agencies. Check with your local Aging agency at the municipal or county level for referrals.

## Donate money and time with local nonprofits.

Work to support community-based living for adults with intellectual/developmental disabilities. You can contact the local offices of disability organizations for more ways to get involved.

## Advocate/Policy issues.

There are many disability-focused advocacy groups in Washington DC, and in every state. The largest is The American Association of People with Disabilities (AAPD), which promotes equal opportunity, economic power, independent living, and political participation for people with all types of disabilities.

WHAT CAN YOU DO TO HELP FILL THE GAPS IN LONG-TERM CARE SUPPORT FOR INDIVIDUALS WHO ARE AGING AND/OR HAVE DEVELOPMENTAL DISABILITIES?

For more information visit:

[The American Association of People with Disabilities \(AAPD\).](#)



## FOR FAMILIES AND PEOPLE WITH I/DD:

### Create a “Letter of Intent.”

This is a document written by the primary caregivers (usually parents) of an adult with I/DD so that others can step in and provide care if necessary. For example, it can be used if the primary caregivers are unavailable due to a short or extended absence or after their death.

This letter should be updated (annually, as needed) to reflect changes to important information and the changing needs, desires, and interests of the adult with special needs.

### Plan for the future.

If you or a loved one is the caregiver of a child or adult with I/DD, do not delay in planning for that person’s future. Have the difficult conversations, seek advice and put things in place as early as possible.

### Get help with your letter.

A [booklet with a form](#) to download was created by the ARC of East Middlesex.

There’s a [separate form](#) for the adult child with I/DD to fill out, with assistance if needed.

You may also access a [Letter of Intent Writing Guide](#) and [Individual’s Planning Questionnaire](#) on the MIMI AND DONA website.



# Discussion Questions

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1. When the film opens, Dona is 64 years old and has never lived away from her mother, Mimi, who is 92.  
*Imagine yourself in Mimi's shoes. What might Mimi be thinking at this stage of life?*
2. Dona's nephew Bo says that "Mimi has simply done everything for Dona" and suggests that Dona is more capable of independent action than she shows.  
*Is it possible for Dona to learn to take care of herself, at age 64?*
3. Dona's family felt they had few options for her placement outside the home.  
*If you had a child or sibling like Dona, what type of living arrangement would you want for this person?*
4. Dona's nephew Keith, who has a son with autism, says, "I occasionally feel like I have to live forever and outlive him."  
*What is behind Keith's statement and how do you feel about it?*
5. Parents must frequently choose what they think is best for their children. This becomes more complicated when the child is an adult with an intellectual disability.  
*How much do Dona's wishes matter in this scenario?*
6. Dona struggles to adapt to her new home while Mimi initially regrets moving Dona.  
*What could have made the transition easier for both Dona and Mimi?*
7. Mimi did not make plans for Dona until she reached a very advanced age.  
*What keeps us from making arrangements in advance concerning our own aging and eventual demise?*
8. With the incidence of autism now 1 in 68 children, there will be many more older adults with autism who will need help after their parents pass away.  
*Who should provide that help? What is the role of the family? Of the government?*
9. Dona's sister Merrily steps in when Mimi can no longer manage Dona's care.  
*How do you feel about the sibling's response to their situation?*
10. The film celebrates the love of Mimi and Dona while also showing the heartbreak of their separation.  
*What do you find most upsetting/inspiring about the film and why?*

[State/Area Agencies on Aging Online Locator](#)

## AGENCIES AND ORGANIZATIONS

[State/Area Agencies on Aging \(AAA\)](#)  
[1-800-677-1116](#)

There are 629 Area Agencies on Aging located in 42 states, and the other eight (AK, DE, NV, ND, NH, RI, SD and WY) use their State Agencies on Aging as the primary point of contact for local resources. Each Area Agency on Aging can provide a range of free assistance, including case management to help low-income seniors find the most appropriate resources where they live. They also help families understand and access public benefits, including Medicare and Medicaid as well as provide caregiving training, respite care, and help with problem solving, including connecting to ombudsman services regarding complaints about long-term care facilities.

[Center for Disability and Aging Policy “No Wrong Door” Online Locator](#)

[Center for Disability and Aging Policy](#)

There is a national effort under the US Department of Health and Human Services to bring together all the different federal agencies that intersect across aging and disability departments to create a “No Wrong Door” system to support state efforts to streamline access to long-term services and support options for older adults and individuals with disabilities. Twenty-five states are now piloting programs under this “No Wrong Door” approach.

[Alzheimer’s Association website](#)

[Alzheimer’s Association](#)  
[24/7 Helpline: 1-800-272-3900](#)

National website with information on Alzheimer’s disease symptoms, diagnosis, stages, treatment, care and support resources, with links to local chapters.

[Easter Seals website](#)

[Easter Seals](#)

A national network of programs such as adult day services, in-home support, community mobility options, wellness programs and support for family caregivers.

## The Arc: For People With Intellectual and Developmental Disabilities

The Arc promotes and protects the human rights of people with intellectual and developmental disabilities and actively supports their full inclusion and participation in the community throughout their lifetimes.

## Family Caregiver Alliance 1-800-445-8106

Family Caregiver Alliance supports and sustains families nationwide caring for loved ones with chronic, disabling health conditions. Their Family Care Navigator helps family caregivers locate programs and services nearest their loved one—living at home or in a residential facility. Resources include government programs, legal resources, disease-specific organizations and more.

## National Down Syndrome Society (NDDS) 1-800-221-4602

In recognition that people with Down syndrome are living much longer than before, NDDS has created new resources to assist families in the aging process with special sections devoted to housing, staying socially connected, coordination of care and end of life considerations.

## United Cerebral Palsy (UCP)

Some people with CP may lose no more function than might be expected from the normal aging process, but for some, new physical problems can emerge as people get older.

[The Arc website](#)

[Family Caregiver Alliance Family Care Online Navigator](#)

[National Down Syndrome Society \(NDDS\) website](#)

[United Cerebral Palsy \(UCP\) website](#)

## Books

All titles below are available for purchase through [Amazon.com](https://www.amazon.com). Or, check your local public library for availability.

*Community Supports for Aging Adults with Lifelong Disabilities*, by Matthew Janicki and Edward Ansello

*Activities With Developmentally Disabled Elderly and Older Adults (Activities, Adaptation and Aging, Vol 15, No 1 & 2)*, by M. Jean Keller

*Thicker Than Water: Essays by Adult Siblings of People with Disabilities*, by Don Meyer

*The Siblings Survival Guide: Indispensable Information for Brothers and Sisters of Adults With Disabilities*, by Don Meyer and Emily Holl

*Loud Hands: Autistic People, Speaking* by Julia Bascom  
A collection of essays written by and for Autistic people.

*Family Life*, by Akil Sharma, a novel about a family moving from New Delhi to New York, where the oldest son is brain damaged from a near-drowning accident. Listed on one of the Ten Best Books of 2014 by the *New York Times Book Review* and *New York Magazine*.

*The Revised Fundamentals of Caregiving: A Novel*, by Jonathan Evison about a middle-aged man who became a caregiver to a 19-year-old who is in the advanced stages of Duchenne muscular dystrophy.

# Resources - Websites

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## Websites and PDFs

[AD/DS Connect](#) makes the connection between Down Syndrome and Alzheimer’s disease (started by Dr. Linda Nelson, Professor Emerita, Department of Psychiatry and Behavioral Sciences at UCLA).

The National Task Group (NTG) on Intellectual Disabilities and Dementia has developed [“Guidelines for Structuring Community Care and Supports for People with Intellectual Disabilities Affected by Dementia,”](#) for family members and providers, in PDF format. Another useful NTG publication is their printable PDF brochure on [“Dementia and Intellectual Disabilities.”](#)

[Agricultural Communities for Adults with Autism](#) is a consortium of existing and in-formation organizations focused on sharing best practices and advocating for holistic, agricultural based employment and housing models for adults with autism. The website includes a list of all affiliated residential communities.

[Future Planning Center - The ARC](#) has created an [online, interactive resource](#) to support individuals with I/DD and their families to plan for the future.

[AD/DS Connect website](#)

[The National Task Group \(NTG\) on Intellectual Disabilities and Dementia website](#)

[Agricultural Communities for Adults with Autism website](#)

[The Arc website](#)

# Resources - Articles and Blogs

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## Articles

### “Successful Aging: A Disability Perspective”

Meredith Minkler and Pamela Fadem from Journal of Disability Policy Studies, Spring, 2002

### “Aging and Disability Resource Centers: Scorecard Highlights the Need for Information and Access to Services”

AARP, June 26, 2014

### Easter Seals Sibling Study

Siblings say their sibling with a disability both enhances and challenges their quality of life, and have strong concerns for their financial futures.

## Memoir/Blogs

### A Regular Guy

Laura Shoemaker

### Senior Mama

Bonnie L. Pike

Two of their nine adult children with disabilities are still living at home.

### a moon, worn as if it had been a shell

Elizabeth Aquino

Where poetry, politics, parenting and disability intersect.

MIMI AND DONA (2015)

A Film by Sophie Sartain

Edited by Chris Callister

Featuring Music by Daniel Lanois

Camera by Sophie Sartain

Additional Photography by Ginny Martin  
and Dyanna Taylor

Executive Producers Marta Kauffman  
and Nancy Spielberg

Executive Producer for ITVS  
Sally Jo Fifer

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