

POV

Community
Engagement & Education

DISCUSSION GUIDE

The Grown-Ups

A Film by Maite Alberdi





The Grown-Ups presents an unexplored community: that of adults with Down syndrome. We always talk about children with Down syndrome, yet we are not used to seeing adults, much less older adults, with this syndrome. What will they do during adulthood? What do we call them? These questions are part of a new reality: although people with Down syndrome still age prematurely, they are now living much longer lives. Twenty years ago, the life expectancy of a person with Down syndrome was 25 to 30 years; today it is 60 years. If a 40-year-old woman gives birth to a son with Down syndrome and that son lives to be 60, he will likely outlive her. In other words, we face a demographic change in this group, and the number of people affected by that change is increasing over time.

We are accustomed to seeing parents taking care of their sons and daughters with Down syndrome. It is only very recently, in the last five years or so, that specialized institutions have begun to be called upon to deal with entire classrooms of students with Down syndrome who have been left to their own devices because their parents died before they did. This is a new and growing issue, and not one to which governments or schools have devoted much thought or planning. In an earlier era, even the parents of people with Down syndrome largely assumed they would outlive their children.

I wanted to tell this story by focusing on the situation in Chile, because it's one of the countries with the highest Down syndrome birth rates. Many people with Down syndrome in Chile make it to adulthood, but little thought has been given to their needs as fully autonomous citizens. The law does not recognize their autonomy so that, among other things, their parents are allowed to sterilize them without their consent. There are no employment or educational networks established for people with Down syndrome past the age of 25. Treating them like children negates the accomplishments they have achieved as adults, and as a result they don't feel like self-determined adults who have the same possibilities as others their age. This is what I want the film to consider and convey. As director, I want the viewer to identify with the impotence and the frustration the subjects feel about growing old before their time and without a chance to experience what they want, which results in feeling that their aging process is unfair.

Maite Alberdi

Director, **The Grown-Ups**



Filmmaker Maite Alberdi.

Credit: Álvaro Reyes





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INTRODUCTION

In Santiago, Chile, four middle-aged friends attending a school for individuals with Down syndrome yearn for a life of greater autonomy in a society that marginalizes them. They have completed all their courses and many have been there for longer than their teachers. Yet, despite jobs, dreams and adult relationships, these 45- to 50-year-olds fight against perceptions that they are children.

The Grown-Ups (60 min.) is a humorous and, at times, sad and uncomfortable look at the friends' struggle against constant interference from well-intentioned family members, teachers, the government, and even the church. The situation creates a limbo where they fall in love, but are never permitted to marry. They hold jobs, but never earn enough to become independent. Determined to pursue their dreams, group members challenge us, along with the people in their lives, to differentiate between protection and smothering.





The Grown-Ups is well suited for use in a variety of settings and is especially recommended for use with:

- **Your local PBS station**
- **Groups that have discussed previous PBS and POV films relating to Down syndrome or people with disabilities, including *Neurotypical*, *Best Kept Secret*, *If I Can't Do It*, and *Freedom Machines*.**
- **Groups focused on any of the issues listed in the “Key Issues” section**
- **High school students, youth groups and clubs**
- **Faith-based organizations and institutions**
- **Independent living centers**
- **Cultural, art and historical organizations, institutions and museums**
- **Civic, fraternal and community groups**
- **Academic departments and student groups at colleges, universities and high schools**
- **Community organizations with a mission to promote education and learning, such as local libraries.**

The Grown-Ups is an excellent tool for outreach and will be of special interest to people looking to explore the following topics:

- **dignity**
- **disability**
- **discrimination**
- **Down syndrome**
- **fair wages**
- **independent living**
- **individual rights**
- **marriage**
- **relationships**
- **rights of individuals with disabilities**
- **social work/social welfare agencies**
- **special education**
- **stereotypes**

USING THIS GUIDE

This guide is an invitation to dialogue. It is based on a belief in the power of human connection, designed for people who want to use **The Grown-Ups** to engage family, friends, classmates, colleagues and communities. In contrast to initiatives that foster debates in which participants try to convince others that they are right, this document envisions conversations undertaken in a spirit of openness in which people try to understand one another and expand their thinking by sharing viewpoints and listening actively.

The discussion prompts are intentionally crafted to help a wide range of audiences think more deeply about the issues in the film. Rather than attempting to address them all, choose one or two that best meet your needs and interests. And be sure to leave time to consider taking action. Planning next steps can help people leave the room feeling energized and optimistic, even in instances when conversations have been difficult.

For more detailed event planning and facilitation tips, visit www.pov.org/engage





What Is Down Syndrome?

In order to understand what Down syndrome is, the terms “genes” and “chromosome” must first be defined. Genes are the codes responsible for inherited traits passed on from parent to child, like blue eyes or red hair. They are contained in a person’s chromosomes, and most humans have 23 pairs of chromosomes. Down syndrome occurs when a person has an extra copy of a chromosome, specifically chromosome 21. This additional chromosome causes certain developmental and intellectual delays, as well as unique physical traits, such as eyes that are slanted upward, shorter height and muscle weakness. Additionally, people with Down syndrome are more likely to have certain health conditions, including congenital heart defects, obesity, thyroid disorders, hearing problems and Alzheimer’s disease. Each person with Down syndrome is different, however, and may or may not present any or all of these features.

According to the Centers for Disease Control and Prevention, one in every 700 babies is born with Down syndrome and it is estimated that around 6,000 babies are born with Down syndrome in the United States each year. Although there are increased rates of Down syndrome in babies born to mothers over age 35, Down syndrome has not been connected to factors of race, socioeconomic status, nationality or the actions of parents during pregnancy. The life expectancy of a person with Down syndrome has increased substantially over time, with most people with Down syndrome surviving past 50 today. This is in comparison to the early 20th century, when babies born with Down syndrome were unlikely to survive infancy.

Sources

Centers for Disease Control and Prevention. “Birth Defects: Data and Statistics.”
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Merriam-Webster. “Chromosome.” <https://www.merriam-webster.com/dictionary/chromosome>

Merriam-Webster. “Gene.” <https://www.merriam-webster.com/dictionary/gene>

“What is Down Syndrome?” <http://www.ndss.org/Down-Syndrome/What-Is-Down-Syndrome/>

World Health Organization. “Genes and Human Disease.”
<http://www.who.int/genomics/public/geneticdiseases/en/index1.html>

History of Down Syndrome in the United States

Down syndrome is named for an English doctor, John Langdon Down, who published what is considered to be the first accurate description of the condition in 1866. Down was a prominent advocate at the time for people with intellectual disabilities. In the 19th century and into the early 20th, babies born with Down syndrome rarely lived past infancy. By 1929, life expectancy had reached 9 years old, and as recently as the 1980s life expectancy for a person with Down syndrome did not surpass 25. As a result, many babies born with Down syndrome were left to die of starvation immediately after birth or were institutionalized in poorly run medical facilities until they died from chronic health problems.

As medical advancements progressed in the mid-to-late 20th century, however, doctors were better able to treat babies with Down syndrome and mitigate the challenges they face in early childhood. Additionally, Down syndrome advocacy organizations like the National Down Syndrome Society and the National Association for Down Syndrome were founded in the 1960s and 1970s, and advances were made in the care and treatment of children with Down syndrome.

In 1975, Congress passed the Individuals With Disabilities Education Act, ensuring that children with intellectual and developmental disabilities had the right to attend public school. In 1990, the Americans with Disabilities Act prohibited discrimination based on disability in regard to access to housing, education, employment and other circumstances.

Sources

The Arc. “Civil Rights Issues for People With Disabilities.”
<http://www.thearc.org/what-we-do/public-policy/policy-issues/civil-rights>

National Association for Down Syndrome. “History of NADS.”
<http://www.nads.org/about-us/history-of-nads/>

National Down Syndrome Society. “What is Down Syndrome?”
<http://www.ndss.org/Down-Syndrome/What-Is-Down-Syndrome/>





Adults with Down Syndrome

A longer life expectancy means that people with Down syndrome are now facing challenges that were virtually nonexistent just a few decades ago. Throughout adolescence and into adulthood, people with Down syndrome experience the same interests and desires as their peers. However, as they come of age, they face obstacles that their peers do not, including issues of housing, employment and relationships that are unique to people with intellectual or developmental disabilities.

Housing

Some people with Down syndrome choose to continue living with their parents even after they've reached adulthood, in some cases because they still require regular care. Those who do leave home have a variety of other options, including group homes, assisted living or student housing for those who are accepted to university. Assisted living situations allow some degree of independence; support services are provided according to the individual's needs, but it is possible for a person with Down syndrome to live alone with limited assistance. Others may choose (or be placed in) group homes. In a group home, people with Down syndrome live communally with other people with intellectual and/or developmental disabilities and are supervised.

Developmental disability advocates emphasize the need to give individuals as much agency as possible when making housing decisions, but options can be narrowed due to finances, the age or availability of caregivers and the relative ability of the person being housed.

Employment

Employment opportunities for people with Down syndrome are limited. Some individuals are able to join the regular workforce and earn competitive wages. What is more common, however, is for people with Down syndrome to be employed in "supported" or "sheltered" work environments. A person working in a "supported" job is part of the regular workforce, but they receive an extended orientation to ensure they can be successful in their chosen profession. A "sheltered" work environment is located outside of the regular labor force in a workshop setting, similar to the cooking class featured in **The Grown-Ups**. In these settings, the person with Down syndrome or other intellectual disability is paid according to their output compared to a typical worker, meaning they generally earn less than minimum wage.

These kinds of programs are not found in every state, and long-term support is especially rare.

Most people with Down syndrome want to work. Despite this, the majority of people with Down syndrome are unemployed or underemployed. According to the United States Bureau of Labor Statistics, "the percentage of working age people with disabilities in the labor force is about one third that of persons with no disability." Even with the Americans with Disabilities Act in place to prevent discrimination based on disability, one third of all employment discrimination allegations with the United States Equal Employment Opportunity Commission are filed by people claiming to have been discriminated against due to a disability.

Relationships

The Grown-Ups explores Anita and Andrés' desire to get married. As they discover in the film, it is not legal for them to marry in Chile. In the United States, however, it is legal for people with Down syndrome and other intellectual or developmental disabilities to get married. Despite misconceptions that people with Down syndrome are childlike, they experience the same emotional needs and sexual desires as other adults, and dating and marriage can be part of life as an adult with Down syndrome.

People with Down syndrome who wish to have children can do so, but often face additional challenges. Only about half of all women with Down syndrome are fertile, while very few men with Down syndrome can have children. It used to be believed that men with Down syndrome could not reproduce at all, but it is now understood that while most men with Down syndrome are infertile, it is possible for some men with Down syndrome to have children.

Sources

The Arc. "Still in the Shadows with Their Future Uncertain: A Report on Family and Individual Needs for Disability Supports, 2011." <http://www.thearc.org/document.doc?id=3672>

National Down Syndrome Society. "Employment & Volunteer Work." <http://www.ndss.org/Resources/Transition-and-Beyond/Employment-Volunteer-Work/>

National Down Syndrome Society. "Life After High School." <http://www.ndss.org/Resources/Transition-and-Beyond/Life-After-High-School/>

National Down Syndrome Society. "Sexuality & Down Syndrome." <http://www.ndss.org/Resources/Wellness/Sexuality/Sexuality-and-Down-Syndrome/>



Selected People Featured in **The Grown-Ups**

Rita - Age 50, feels that her mother still treats her like a child



Ricardo - Age 45, the intellectual leader of the group, working two jobs but unable to earn enough to live independently



Anita - Age 50, wants to marry Andrés



Andrés - Age 45, wants to marry Anita

GENERAL DISCUSSION QUESTIONS

Immediately after the film, you may want to give people a few quiet moments to reflect on what they have seen or pose a general question (examples below) and give people some time to themselves to jot down or think about their answers before opening the discussion:

- If a friend asked you what this film was about, what would you say?
- If you could ask anyone in the film a single question, what would you ask?
- Describe a moment or scene in the film that you found particularly disturbing or moving. What was it about that scene that was especially compelling for you?

At the end of your discussion, to help people synthesize what they've experienced and move the focus from dialogue to action steps, you may want to choose one of these questions:

- What did you learn from this film that you wish everyone knew? What would change if everyone knew it?
- If you could require one person (or one group) to view this film, who would it be? What do you hope their main takeaway would be?
- Before the film, when I encountered a person with Down syndrome I _____. Now I will _____.
- Complete this sentence: I am inspired by this film (or discussion) to _____.



Confronting Stereotypes

How did the film confirm or challenge your ideas about people with Down syndrome?

What did you see in the film that was familiar? How are the issues that the characters face like the issues you and your friends face? How are they different?

We see Ricardo trying to help his grandmother. She responds by calling him “stupid.” What did you think of Ricardo’s response? Have you seen or heard people similarly insult a person with Down syndrome (or another disability)? Why do you suppose some people see this sort of abusive behavior as acceptable? What could you say or do to address mean-spirited treatment of people who might be vulnerable?

How might the view of people with Down syndrome change if societies’ focus was on all the things that Ricardo, Andrés, Anita and Rita could do instead of the things that challenge them?

Conscious Adults

The group attends a school where they are encouraged to be “crazy passionate” about being “conscious adults.” To Anita, being a “conscious adult” means, she says, “We can do what we want. We can do things by ourselves.” What are the benefits and drawbacks of this message for the people featured in the film?

When Patty suggests to Anita that her tracksuit might not be the sexiest wardrobe choice for a girl coming out of Andrés’ birthday cake, Anita responds, “Who cares, Patty? I like it.” Is Patty’s advice helpful? Should she push Anita to meet a standard set by the neurotypical world? How would you balance trying to help individuals with Down syndrome learn to live in the world with appreciation for their own unique perspective? Should people insist that people with Down syndrome be like everyone else? What can everyone else learn from them?

When Rodrigo and Rita get into a fight in the kitchen, Rita looks for their teacher to intervene, but she is told to stick up for herself: “It’s your problem. You take care of it. You will go in as a strong woman. Keep your chin up. Attitude, head up, and you set him straight.” What happens to Rita or her friends when they do just that with their teachers or parents?

Anita says, “Fathers and mothers should take care of their children, but they shouldn’t overdo it.” Did you see any instances in the film where you thought parents were “overdoing it”?

School and Work

Andrés is surprised to discover that he can’t afford a ring for Anita, and Ricardo is disappointed that despite working two jobs, he only earns the equivalent of 15 dollars per month when he needs 500 dollars per month to live independently. Ricardo: “I have two jobs. But I’m really tired. I work and work, but I don’t earn anything. And I don’t know what to do.” How would you respond to the frustrations of these men?

How might a business benefit from hiring someone with Ricardo’s dedication, persistence, leadership and temperament?

At his second job, Ricardo calms one of the nursing home residents. How is his unique temperament an advantage in this situation?

Ricardo leads the group as they try, unsuccessfully, to sell baked goods door to door. If you were coaching them, how would you suggest they improve their sales techniques?

Anita complains, “I’m sick of school. So bored. I’ve been here for 40 years. I’d like to do other things, besides school. I don’t want to always be cooking in the catering class. I shouldn’t have to always be here. I can’t do the same thing my whole life.” What do you think would change for Anita if people believed she was capable of more? What would change if the school or community had the capacity to offer different types of programs and work for adults with Down syndrome?

Love and Marriage

Several of the friends seem to get their ideas from TV and movies, especially when it comes to ideas about marriage, love and sex. What are the benefits and potential dangers of letting people absorb cultural norms from media?

According to Chilean law, people with Down syndrome cannot legally be married. Do you support that law? Why or why not?

Though civil law says that people with Down syndrome can’t be married, the Catholic Church will consider performing a religious marriage ceremony on a case-by-case basis. When Andrés approaches a priest about marrying Anita, the priest explains, “The church asks that you express the maturity of someone that is at least 18 years old, that you be conscious of the decisions you make... and also that you have the support of family.” Do you think these are wise rules? Given



these requirements, do you think that the Church should approve a marriage between Anita and Andrés?

Anita's mother refuses her daughter permission to marry. Why do you think that is?

Andrés describes himself as a "womanizer." How would you explain to him that such behavior dishonors women?

Andrés and Anita ask the school to provide them with a private space where they can be intimate. If you were the director of the school, how would you respond to that request?

When Andrés' sisters stop paying his school fees and forces him to move away, Luis tries to comfort Anita, saying, "Andrés' siblings decided this. Andrés didn't decide to leave. In your case, your mother decided you should stay." What was your reaction to the decisions that resulted in pulling the couple apart?

Additional media literacy questions are available at:
www.pbs.org/pov/educators/media-literacy.php

Taking Action

- **Locate the independent living centers in your area and arrange a visit to get to know the people there. Find out what they need and how you can help.**
- **In conjunction with local Rotary clubs or other business associations, host an information session on hiring people with Down syndrome (or other disabilities) for prospective employers.**
- **Consider raising funds for local child care professionals and teachers to receive professional development training on educational methods that help children with Down syndrome develop basic academic and life skills.**
- **Start a local support group for families of individuals with Down syndrome. If such groups already exist, publicize their resources so that new parents can find them easily.**





FILM-RELATED WEB SITES

THE GROWN-UPS

www.thegrown-ups.com

The film's website provides information about the film and also suggests ways to support campaigns to increase wages and work opportunities for people in Chile with disabilities

Original Online Content on POV

To further enhance the broadcast, POV has produced an interactive website to enable viewers to explore the film in greater depth. The **The Grown-Ups** website—www.pbs.org/pov/thegrownups—offers a streaming video trailer for the film; an interview with the filmmaker; a list of related websites, articles and books; a downloadable discussion guide; and special features.

COOCENDE

www.coocende.cl

The website (in Spanish) of the school featured in the film provides additional information about its programs.

DOWN SYNDROME EDUCATION ONLINE

www.down-syndrome.org

Stories and resources related to equipping people with Down syndrome with independent living skills are available on this website.

GLOBAL DOWN SYNDROME FOUNDATION

www.globaldownsyndrome.org/about-down-syndrome/misconceptions-vs-reality

This organization offers sources that are useful for sorting through the myths and facts about people with Down syndrome.

NATIONAL DOWN SYNDROME SOCIETY

www.ndss.org

The website of this human rights organization that advocates for individuals with Down syndrome includes information for parents of children with Down syndrome and an entire section on issues related to aging:
<http://www.ndss.org/Resources/Aging-Matters/>.



HOW TO BUY THE FILM

For information on how to order **The Grown-Ups** for home use, visit pbs.org/pov/thegrownups.



Produced by American Documentary, Inc., POV is public television's premier showcase for nonfiction films. The series airs Mondays at 10 p.m. on PBS from June to September, with primetime specials during the year. Since 1988, POV has been the home for the world's boldest contemporary filmmakers, celebrating intriguing personal stories that spark conversation and inspire action. Always an innovator, POV discovers fresh new voices and creates interactive experiences that shine a light on social issues and elevate the art of storytelling. With our documentary broadcasts, original online programming and dynamic community engagement campaigns, we are committed to supporting films that capture the imagination and present diverse perspectives.

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POV Digital www.pbs.org/pov

Since 1994, POV Digital has driven new storytelling initiatives and interactive production for POV. The department created PBS's first program website and its first web-based documentary (*POV's Borders*) and has won major awards, including a Webby Award (and six nominations) and an Online News Association Award. POV Digital continues to explore the future of independent nonfiction media through its digital productions and the POV Hackathon lab, where media makers and technologists collaborate to reinvent storytelling forms. @povdocs on Twitter.

Front cover: The main characters of the film.
Credit: Álvaro Reyes

POV Community Engagement and Education

POV's Community Engagement and Education team works with educators, community organizations and PBS stations to present more than 650 free screenings every year. In addition, we distribute free discussion guides and standards-aligned lesson plans for each of our films. With our community partners, we inspire dialogue around the most important social issues of our time.

American Documentary, Inc. www.amdoc.org

American Documentary, Inc. (AmDoc) is a multimedia company dedicated to creating, identifying and presenting contemporary stories that express opinions and perspectives rarely featured in mainstream media outlets. AmDoc is a catalyst for public culture, developing collaborative strategic engagement activities around socially relevant content on television, online and in community settings. These activities are designed to trigger action, from dialogue and feedback to educational opportunities and community participation.

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