

## *Body & Soul: Diana & Kathy*

A film by Alice Elliott

Welcome Change Productions, NYC. 2007

### INTRODUCTION TO THE STUDY GUIDE

This guide to viewing *Body & Soul: Diana & Kathy* is designed to help teachers begin a conversation with their students about disability, diversity, inclusion, advocacy and accessibility. This dialogue will present an opportunity to explore our biases about people with intellectual and physical disabilities like Down Syndrome and cerebral palsy, increase our understanding, and see ways we can support people viewed as “different.” Use the film and guide to enhance a social studies or health unit, promote bias awareness, and inspire community service. Keep these guidelines in mind as you lead the discussion:

- Be direct in talking about disabilities, don’t ignore them. Read the accompanying Definitions about disability so you can answer basic questions that might come up. Use the list of resources provided to research more complex questions.
- Stress that it’s most helpful to acknowledge what a person can do well rather than dwell on what a person cannot do.
- Remind students that a person is more than his/her disability. Don’t limit with labels. Be mindful of word choices, use person-first language (e.g., Diana is a person who has Down Syndrome) and the term Intellectual Disability instead of Mental Retardation.

The guide is divided into nine sections: Summary / Background / Preparing Your Students / Viewing & Responding to the Film / Deepening Students’ Understanding of the Film / Connecting the Film to Students’ Lives / Possible Activities / Definitions & Resources / Frequently Asked Questions. You will need two class periods to define the issues, view the film, and have a meaningful discussion. A double period would be ideal for a brief study. Several periods would allow deeper discussion and group projects.

**SUMMARY** “*Body & Soul: Diana & Kathy*” is a 40 minute documentary about two life-long friends Diana Braun and Kathleen Conour who have made their home in Springfield, Illinois. Diana drives, cooks, shops, and has been Kathy’s personal assistant and friend for the past 37 years. Remarkably, Diana has Down Syndrome, a genetic condition that gives her one extra chromosome and a lower IQ. Kathy on the other hand is 61, has a college degree in English, but is non-verbal, and has had cerebral palsy since her birth. For 37 years they have lived together, forging a unique symbiotic relationship that has allowed them to live independently and be active in their community where fifty years ago they would have been institutionalized. As part of their ongoing activist efforts to demystify disability, Diana and Kathy invited Alice Elliott, Director of Welcome Change Productions into their home to create their film, *Body & Soul: Diana & Kathy*. Their film has been screened around the United States and has received numerous awards, including the 2007 AAIDD Media Award, 2007 TASH Positive Images in Media Award, and the 2008 Best of Festival Award at Superfest XXVIII. Kathy and Diana have also been awarded the Illinois Governor’s Human Rights Award and the 2008 Justin Dart Distinguished Citizens of the Year Award.

**BACKGROUND** The road to this documentary began in 2001 when Diana and Kathy approached Alice Elliott and asked her to make a film about them. In 2002, Alice took her camera and traveled to Springfield, Illinois to record Kathy and Diana's unique friendship. Diana and Kathy are not only friends, but advocates as well. They continue to explore innovative solutions for people with disabilities. Having successfully lived outside of institutions for over 35 years, they have become advocates for choice in housing for people with disabilities and for funding to follow the person.

Kathy and Diana met at a sheltered workshop three decades ago and vowed to fight to live independent lives. Fearful of being shut away in a nursing home or forced into a state run institution, they broke the rules and escaped the system. Not content to earn menial wages at a sheltered workshop and have their living situation change with the whim of a government appropriation, they moved, built a house, and survived to tell their story. Kathy and Diana are survival geniuses.

Diana and Kathy have established themselves as a tireless dynamic pair of well-known lobbyists and activists in the disability movement. Kathy was even arrested (power chair and all!) during a disability rally. Through the help of a mouth stick and the Pathfinder, a computerized augmented speaking device, Kathy writes articles for national magazines and has a lively email correspondence with leaders in the disability rights movement. Both Diana and Kathy serve on boards and regularly lobby for disability rights in Washington D.C. and throughout the State of Illinois.

Kathy and Diana are part of a vulnerable population that has been terribly oppressed. There is a long history of misinformation, prejudice and discrimination against people with disabilities, including people with Down Syndrome and cerebral palsy. They have often been kept out of public view, cared for privately at home or hidden away in institutions. As recently as 1990, in long-stay institutions, residents with disabilities were rarely provided opportunities to voice their desires and have their wishes heard. Nearly every life decision - from daily choices of what food to eat and what clothes to wear, to long-term planning around how to spend time and what types of support or treatment to receive - was made at the institutional level, irrespective of the abilities and preferences of individual residents. Parents of children with significant disabilities feared for their children's care should the parent die or become incapacitated. In addition, as a result of stigma and discrimination and a traditional emphasis on people's limitations rather than abilities, even people who lived outside of institutions were denied opportunities to control their own lives (Source: <http://www.osmhi.org/?page=238>).

In 1950, family members and others concerned about the treatment of people with intellectual disabilities founded The Arc to educate the public and advocate for people with intellectual disabilities. Through the efforts of Arc and other organizations dedicated to helping people with disabilities, perceptions of people with disabilities have changed. Landmark laws passed in the early 1970s gave children with disabilities 10% of the spaces in Head Start classes and the right to a free education in "the least restrictive environment." In 1999, the Supreme Court handed down one of the most significant decisions in the history of the disability rights movement: *Olmstead v. L.C.* [527 U.S. 581 (1999)]. In *Olmstead*, the Court ruled that Title II of the Americans with Disabilities Act prohibits the unnecessary institutionalization of persons with disabilities. In the words of the Supreme Court, services to persons with disabilities must be provided "in the most integrated setting possible." Today, people with disabilities are integrated into schools, communities, and the

workplace, and increasingly recognized for what they can do, rather than being identified by what they cannot do. But we still have a long way to go.

**PREPARING YOU STUDENTS** Before viewing the film with your students, begin your study with a discussion of intelligence, intellectual disabilities (mental retardation), Down Syndrome, and cerebral palsy:

1. Explore the meaning of intelligence. Ask your students: What is intelligence? What do we mean by intelligence? Aim for a broad definition that goes beyond doing well in school or on tests and includes the ability to adapt to your environment. (Howard Gardner's idea of multiple intelligences believes that people are smart in different ways and intelligence is determined by a society; the kinds of intelligence most valued depend on the kinds of skills and adaptability that society requires.)
2. Explore students' perceptions of "intellectual disability" (including Down Syndrome) by creating a web<sup>1</sup> on the board. Quickly elicit ideas, attitudes, images, and experiences about intellectual disability and put them on the web. Then you might ask students to come up with a definition of intellectual disability from what they know. Make a note of any questions the students have.
3. Repeat the exercise with the words "cerebral palsy". Elicit ideas, attitudes, images, and experiences about cerebral palsy. What does it mean to have CP? Make note of comments and questions the students have.

**VIEWING & RESPONDING TO THE FILM** Introduce the film by showing your students the front cover of the DVD box. Point out the picture of the two women on the front. Tell your students that the women on the cover are advocates, both with disabilities, and that the film is a documentary about Diana Braun and Kathleen Conour and their fight to stay out of institutions. Watch the film in one sitting, if possible. After viewing, ask your students some general questions:

- What caught your attention?
- What feelings came up?
- What images or scenes stand out?
- Did you think anything was funny?
- Did anything surprise you? Why?
- What questions do you have? List them on the board. Use the list of resources and the Frequently Asked Questions appendix to find answers, either as an in-class project or homework assignment.

## DEEPENING STUDENTS' UNDERSTANDING OF THE FILM

- Ask you students: What are the main themes? Elicit their ideas.
- What is the message of the film? Do you agree with this message?

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<sup>1</sup> Write "intellectual disability" on the board or chart paper and circle it. As students volunteer their associations with mental retardation, write those words, phrases, ideas outside the circle, then draw a line from the words to the circle, thus creating a "web. A web is a quick tool for assessing a group's knowledge and attitudes about a subject.

- What do we learn about cerebral palsy, Down Syndrome, community, advocacy, and ourselves from the film?

*If time permits, discuss any of the following questions. If not, go to "Connecting the Film..."*

- The first scene shows Diana helping Kathy out of bed and getting her ready and you see that Kathy needs a lot of help. What was your first impression of Kathy? What was your impression after Kathy spoke using her communication device?
- Both Kathy and Diana have experience with institutions like the Lincoln Developmental Center. What do you think these institutions were like? Would you like to be kept in an institution, to not have choice in your life?
- In order to be qualified for Medicare, Kathy and Diana are not supposed to leave their home to travel and lobby (Medicare only allows visits to 3 places; the doctor, haircuts, or church). Is it fair to place limits (tied to funding) on people with disabilities? Do you think Kathy and Diana should have to stay home?
- How can we as individuals and as a group appreciate differences and stand up to unfair rules the way Kathy and Diana do? Consider the sources of strength and the traditions that sustain people (e.g., friends and family, associations, legislation, communities of faith, doctors, and case managers) that provide necessary support structures.
- Towards the end of the film we learn that, due in part to Kathy and Diana's advocacy, new laws/regulations have been passed that allow Money to Follow the Person, Person-Centered Planning (see Definitions), and mutual supported living arrangements. We also learn that the Lincoln Development Center institution will not reopen. Will this make a difference? What do you think will happen now?
- Kathy and Diana teach us about working hard for what you believe in. We see them take a trip to Washington, D.C. to lobby. Do you believe in something that much? Would you write letters or visit your senators to advocate for what you believe?
- Throughout the film, you see Kathy and Diana use accessible transportation. They have a wheelchair accessible van and take a train that has a ramp for Kathy. Do you think every place is accessible to Kathy? Think about the locations you visit everyday. Are they accessible to someone using a wheelchair? How would this effect Kathy's lifestyle?

## **CONNECTING THE FILM TO STUDENTS' LIVES**

- Ask: Have you ever known anyone like Kathy or Diana? How was s/he treated?
- Ask students to remember a time when they met someone who was "different" in some way but whom they got to know better. Did their attitudes change as they got to know the person? How?

- Ask students to pair up and talk about a time that they saw someone being discriminated against or targeted for being “different.” Ask them to remember a time when they stood up for someone who was “different.” Ask them to talk about a time they saw an adult close to them stand up for someone who was “different.”

*If time permits, discuss any of the following questions or use them for group study.*

- Kathy and Diana are lucky to have each other as friends. Think about other people with disabilities who do not have anyone. What do you think their lives are like? Where would Diana be without Kathy? Where would Kathy be without Diana? Some people call this kind of relationship “symbiotic”. What does that mean? Do you think it is true of Diana and Kathy?
- Kathy grew up with loving parents that ignored doctors’ advice to place her in an institution as her mother wanted to raise her at home. Diana’s parents were abusive, and she was placed in a state institution when she was 8. Did Diana and Kathy’s different upbringings affect them differently?
- Brainstorm a list of Diana’s characteristics with your students; write them on the board or on chart paper. (The list might include: takes care of Kathy, wears glasses, has her driver’s license, cooks, lobbies/makes her views known, gardens, watches TV, etc.) Ask for volunteers: What do you have in common with Diana? What do you admire most about Diana? Do the same for Kathy. (Characteristics might include: is a writer, raised in a loving home, went to college, can balance a check book, broke her hip and had to go to the hospital, cares deeply for her friend Diana).
- After Kathy broke her hip, she worried that she was too much work for Diana and that Diana might want to put her in a nursing home or institution. How would you feel if you were in this situation? How would you feel if you were Diana?
- Kathy’s parents left them some money to live on, they have to carefully apportion their money for rent, utilities, food and medical bills and have little left to spend. Do you set aside part of your allowance or earnings for specific obligations (college, cell phone, etc.)? Is it easy to budget your money?
- Diana overwrites checks because she has a difficult time with numbers. Do you know anyone who has a difficult time with money and balancing his/her checkbook? What happens when you overspend? How did Diana get help?
- Diana has cared for Kathy as her personal assistant for over 37 years. She cleans the house, prepares the meals, and takes care of Kathy’s physical needs. Do you know anyone who radically changed his/her life to be someone else’s caretaker, to make it possible for someone else to have a better life? What are some of the benefits for Diana?
- Have you ever been part of an organization or community that took care of a member that needed help? Did things work out? How did you feel?
- Envision an ideal community. Can you picture a community with diverse members where everyone is welcome? What must happen for this to be possible? What needs do people have

and how are they met (e.g., healthcare, transportation, safety, recreation, etc)? Can you draw a model community?

## POSSIBLE ACTIVITIES

- Compare the AAIDD's definition of intellectual disability/mental retardation with the definition your students developed before viewing the film. (repeat for cerebral palsy)
- Review the Fact Sheet: Summary of Self-Determination insert for group study, either in class or for homework. Ask students to explain their understanding of Self-Determination. Can Diana and Kathy be considered self-determined? Does the right to self-determine apply to everyone? Discuss the fact that 10% of the population will be disabled at some point in their lives. With the teacher's help, evaluate what the students have learned through viewing and discussing *Body & Soul: Diana & Kathy* (Source: National Resource Center on Supported Living and Choice, Center on Human Policy, Syracuse University <http://thechp.syr.edu/determination.pdf>).
- Social Capital is a term used to describe investing in each other to build community. Building Social Capital can be as simple as asking a neighbor if you can pick up something for them at the grocery store. If you would like to learn more, there is a list of 150 Ways to Build Social Capital at [www.bettertogether.org/150ways.htm](http://www.bettertogether.org/150ways.htm).

## DEFINITIONS

**Cerebral Palsy (also referred to as CP):** a term used to describe a group of chronic conditions affecting body movement, posture, and muscle coordination. It is caused by damage to one or more specific areas of the brain, usually occurring during fetal development; before, during, or shortly after birth; or during infancy. "Cerebral" refers to the brain and "palsy" to muscle weakness/poor control. Cerebral palsy itself is not progressive (i.e. brain damage does not get worse); however, secondary conditions, such as muscle spasticity, can develop which may get better over time, get worse, or remain the same. Cerebral palsy is not contagious. *It is not a disease and should not be referred to as such.* Although cerebral palsy is not "curable" in the accepted sense, training and therapy can help improve function. (See **United Cerebral Palsy**, <http://www.ucp.org>)

**Down Syndrome:** a chromosomal disorder characterized by the presence of an extra #21 chromosome. Instead of having 46 chromosomes in each of his/her cells, a person with Down Syndrome has 47. This form of chromosome error, trisomy 21, is found in about 95% of persons with Down Syndrome. The 5% of babies with Down Syndrome who do not have trisomy 21 may have Translocation, Mosaicism or partial trisomy. (See **National Down Syndrome Congress**, <http://www.ndscenter.org>)

**Medicare:** the federal health insurance program for people 65 years of age or older, certain younger people with disabilities, and people with End-Stage Renal Disease. (See **Official U.S. Government Site for People with Medicare**, <http://www.medicare.gov>)

**Intellectual Disability (Mental Retardation):** a disability originating before age 18 that is characterized by significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills. (See **American Association on Intellectual and Developmental Disabilities (AAIDD)**, <http://www.aaid.org>)

**Developmental Disability:** a mental or physical impairment beginning before the age of 22 that alters or inhibits a person from doing at least three of the following: take care of themselves, speak and be understood clearly, learn, walk, make decisions, earn and manage an income, or live on their own. (See **Administration on Developmental Disabilities (ADD)**, <http://www.acf.hhs.gov/programs/add/addabout.html>)

**Self-Determination:** acting as a causal agent in one's life and making choices and decisions regarding one's quality of life free from undue external influence or interference. (See **Wehmeyer**, <http://www.rcep7.org/MoreThanAJob/Mod1/01%20Definition.htm>)

**Independent Living:** a philosophy and a movement of people with disabilities who work for self-determination, equal opportunities and self-respect. Proponents of Independent Living demand the same choices and control in their every-day lives that people without disabilities may take for granted. They want to grow up with their families, go to the neighborhood school, use the same bus, work jobs that are in line with their education and interests, and start families of their own. (See **Independent Living Institute**, <http://www.independentliving.org/>)

**Money Follows the Person:** an initiative to integrate people with disabilities into the community by giving people the freedom to choose where they want to live along with other freedoms that are often restricted by institutional living. The cost of living in the community is 2/3 on average the cost of nursing homes or equivalent institutions, saving the states needed resources and funds. (See **ADAPT**, <http://www.adapt.org/mfp1.htm>)

**Person-Centered Planning:** a new approach to planning and delivering services to people with disabilities that goes beyond the traditional service system. The person-centered approach

no longer bases planning on “services available at the present time” but instead creates a team of people who know and care about the individual with a disability and who come together to develop the supports necessary for that person’s future. (See **Garner and Dietz**, <http://www.ttac.odu.edu/Articles/person.html>)

**Self-Advocacy:** when independent groups of people with disabilities work together for justice by helping each other take charge of their lives and fight discrimination. Self-advocacy teaches everyone how to make decisions and choices that affect our lives so we can be more independent. It teaches us about our rights and our responsibilities. Self-advocacy is the ability to express our thoughts, feelings, and rights about things that are important to us. (*Community Advocacy Press, 1996, p. 6*) (See **People First Conference**, [https://fp.auburn.edu/rse/trans\\_media/08\\_Publications/06\\_Transition\\_in%20Action/chap17.htm](https://fp.auburn.edu/rse/trans_media/08_Publications/06_Transition_in%20Action/chap17.htm))

## RESOURCES

### [www.dianaandkathy.com](http://www.dianaandkathy.com)

**Diana and Kathy** is a website that provides additional resources for the film and updates from Diana and Kathy. If you would like to contact Diana or Kathy about any of their activities, please e-mail [D&K@welcomechange.org](mailto:D&K@welcomechange.org).

### [www.welcomechange.org](http://www.welcomechange.org)

**Welcome Change** is the production company for *Body & Soul: Diana & Kathy*. The website tells about the making of the documentary, about Kathy and Diana and about organizations working for change and tolerance. The site also has links to other organizations and the documentary *The Collector of Bedford Street*. If you would like to know more about *Body & Soul: Diana & Kathy*, the film, please e-mail the Director Alice Elliott at [director@welcomechange.org](mailto:director@welcomechange.org)

### [www.thearc.org](http://www.thearc.org)

**The Arc** is the national organization of and for people with intellectual disability and related developmental disabilities and their families. It is devoted to promoting and improving supports

and services for people with intellectual disability and their families. The association also fosters research and education on preventing intellectual disability in infants and young children.

### [www.aidd.org](http://www.aidd.org)

**The American Association on Intellectual and Developmental Disabilities (AAIDD)**, formerly known as the American Association on Mental Retardation (AAMR), is the oldest and largest interdisciplinary organization of professionals (and others) concerned about intellectual disability and related disabilities. AAIDD promotes progressive policies, sound research, effective practices, and universal human rights for people with intellectual disabilities.

### <http://www.ucp.org>

**United Cerebral Palsy (UCP)** is the leading source of information on cerebral palsy and is a pivotal advocate for the rights of persons with any disability. As one of the largest health charities in America, the UCP mission is to advance the independence, productivity and full citizenship of people with disabilities through an affiliate network.

### <http://www.cilberkeley.org>

**The Center for Independent Living (CIL)** is the world’s first organization run by and for people with disabilities. Founded in 1972, CIL supports disabled people in their efforts toward independence. CIL encourages people with disabilities to make their own choices and works to open doors in the community to full participation and access for all.

### [www.tash.org](http://www.tash.org)

**TASH** is an international membership association leading the way to inclusive communities through research, education, and advocacy. TASH members are people with disabilities, family members, fellow citizens, advocates, and professionals working together to create change and build capacity so that all people, no matter their perceived level of disability, are included in all aspects of society.

Please also view our list of resources and organizations on the *Body & Soul* website.

## FREQUENTLY ASKED QUESTIONS

Alice Elliott, the director of *Body & Soul: Diana & Kathy*, responds to frequently asked questions.

### **How is Kathy now?**

She had an operation on her hip in January of 2007 and her upper femur was removed. Since that operation she has been in much less pain and is able to travel.

### **How do Diana and Kathy communicate? Are they really understanding each other?**

Diana and Kathy have lived together for more than 37 years. Diana is extremely patient and doesn't mind being wrong, so sometimes she guesses, but most of the time she recognizes what sounds Kathy makes.

### **What happened to Diana's brothers and sisters?**

Diana has been able to find a few of her brothers and sisters, but the family was split up when the children were taken away. Diana was the only child sent to an institution; the others went to foster families.

### **Where was Diana's mother buried?**

Diana's mother died in Tennessee. Her church and friends there paid for her to be cremated and her ashes to be sent back to a family plot in southern Wisconsin. That is where the interment in the film took place.

### **How much do you, as the filmmaker, influence the action?**

Very little. For example, I tried to get Diana to visit her mother, but as you see in the film, Diana's mother refused to see her. I was pretty much along for the ride.

### **Why did it take you five years to make the film? And how many hours did you shoot?**

I was hoping that Diana and her mother might have a reconciliation. When her mother died, we knew that couldn't happen. I shot about 100 hours of footage.

### **What are you working on now?**

For the last year and a half I have been shooting a documentary about a Down Syndrome couple in the Syracuse area of New York state that got married. He is Hindu and she is Christian, and they have allowed me to follow them during their first two years of marriage.

### **Why didn't Diana and Kathy sue Amtrak?**

Diana and Kathy made a fair settlement with Amtrak out of court.

### **What happened with Medicare?**

Diana and Kathy lost their home healthcare nurse. They now pay from their own pocket for a private nurse to come and change Kathy's catheter bag. The hospital is not well equipped with a table that lowers and is safe and comfortable for Kathy.

### **What is the future for Diana and Kathy?**

They are very active and are traveling all over the country showing the film. Go to our website: [www.welcomechange.org](http://www.welcomechange.org) to see if they will be having a screening near you. You may also invite them to speak and screen the film by contacting [info@welcomechange.org](mailto:info@welcomechange.org).

*Body & Soul: Diana & Kathy* will be screened on public television during 2008 & 2009.