

**USE YOUR WORDS:
A CAMPAIGN DESIGN**

Honors Capstone

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IDEA BACKGROUND

June 7, 1994 is doubtless one of the most influential days of my entire life. June 7, 1994 was the day my sister Caroline was born. Growing up as Caroline's older sister has without a doubt set in motion much of what my life is today.



Caroline was born with Angelman Syndrome. Angelman syndrome is a rare genetic disorder, with a prevalence rate of 1 in 12,000 – 20,000 people. There are an estimated 1000-1500 in the United States and Canada (NIH).

Those with this particular disorder show developmental delay, speech impairment—none or minimal use of words, with higher functioning non-verbal communication skills than verbal communication skills, issues with movement and balance, as well as several unique behavioral identifiers: any combination of frequent laughter and smiling (generally happy demeanor), easily excitable personality, often accompanied by hand-flapping movements, and short attention span. More than 80% of people with Angelman have seizures. Associated characteristics (occurring in between 20-80% of cases) include a flat back of the head, protruding tongue and tongue thrusting (accompanied by sucking/swallowing disorders), hypopigmented skin and eyes, wide mouth with wide-spaced teeth frequent drooling, uplifted, flexed arms during walking, increased sensitivity to heat, sleep disturbance, and a particular fascination with water.

There are several technical ways that Angelman Syndrome can occur, but my sister's in particular is caused by something called *uniparental disomy*. Here's a quick high school bio

review: A person is usually born with 46 chromosomes, half of which are inherited from the mother, and half from the father. Variances in that process produce genetic disorders.

Uniparental disomy is one of those variances. In Angelman Syndrome, it means someone is born with two paternal chromosome 15. Those with this particular variance lack the UBE3A gene that is contributed by the maternal chromosome 15.

A more common example of this is Down Syndrome. For three different technical reasons, people with Down Syndrome are born with 47 chromosomes instead of 46—they have three sets of chromosome 21.

What does all this really mean?

For me, it means a life of advocacy.

For Caroline's entire life, people have had strong reactions to her. As is consistent with her syndrome, she's an incredibly happy, friendly, outgoing person. Sometimes I'd be out in public with her, and for whatever reason a certain person really intrigued her; She particularly loves babies and young children. Many times, despite best efforts, that meant her running over to them to wave and say hi, or pat and kiss their hand, smile widely, and try to give them a hug. Reactions ran the gamut. All were shocking in their own way.

Sometimes people would draw back in utter revulsion, or with fear-- especially parents with young kids. (This is more understandable to me now that Caroline is 17. It was not so understandable to me when I was 10 and Caroline was 6.)

Sometimes people would reflect an incredible adaptability and sensitivity. They would smile back, and respond to me or my mother's profuse apologies with, "No, really. It's completely okay." And then to Caroline, "Hi, what's your name?" To which she could never respond. Caroline is nonverbal—she cannot speak, but she has a voice.

The only speech Caroline can verbalize with confidence is “ma.” My mother’s life is a constant chorus of “mama, ma-ma-ma, ma,” a blessing and a curse. After years of speech therapy, we had cultivated a “ba,” a “wuh,” and a “pa” sound. Without consistent practice and training, those skills have waned a bit.

Many families of people with intellectual or developmental disabilities, like Caroline, are uncomfortable with taking them out in public. There are specific behavioral challenges, and every case is different. My family was different, and until the day I die I will respect my parents for that, because it is one of the most formative reasons for who I am.

We went to church as a family. We went to dinner at restaurants as a family. We ran errands and went to the movies as a family. That meant all of us. That included Caroline. That was utter normalcy for my nuclear family. It was anything but normal for everyone else.

Every single time we go out, people stare. When I was younger, it made me so angry I would cry. It seemed so unfair. What was she doing? Why were they so mean, when she wasn’t hurting anyone? Why were they so suspicious? Why were they so afraid?

My parents had different reactions, too. I inherited my father’s temper—he was inflamed any time anyone had the gall to stare open-mouthed, or make rude comments within earshot. My mother is a much more patient person. She would say, “They are afraid of what they are not familiar with. This is an opportunity. If you’re upset about something, do something about it.”

So I did. I rehearsed ways to approach people. It ran some pattern like this, “Hello. I noticed you were looking at/ talking about my sister, Caroline. I was wondering if you had any questions I could answer for you.” I don’t recall a time when anyone responded to me. It was as though because she didn’t really understand how they were intruding on her, it

didn't matter, but because they understood that my calling them out was an intrusion, it was incredibly offensive.

Over the years on half-days of school, I would spend the second part of the day volunteering in Caroline's classroom. We were lucky enough to live in one of the best school districts for special education. From an early age, Plano ISD made one of the best efforts nationwide to 'mainstream' special education students—which simply means to place them in general education classrooms whenever possible. The children Caroline grew up going to school with saw very little division between the 'regular ed' classroom and the 'special ed' classroom.



She is the inspiration for my advocacy. In high school I organized my school's group for the "March for Respect," an annual solidarity march through the Dallas West End. In college, my first internship was in the

public relations department of the national headquarters of The Arc. I went back to The Arc after a summer interning at home at The American Red Cross – Dallas Area Chapter, and they later hired me on as Brand Coordinator to help implement the organization's rebrand, which spans more than 700 chapters nationwide.

The Arc, according to The Cone Nonprofit Power Brand survey, was the ninth most influential nonprofit in The United States. Yet in brand recognition, it ranks at the bottom of the list—96th.

This speaks to something I've known all along. An enormous number of people affected by intellectual and developmental disabilities (I/DD) see it as a completely private issue. The policy and social issues associated with I/DD are pushed to the back-burner. Why?



Caroline understands much more than she can communicate. I've often wondered what it feels like to be stuck behind her eyes, with only "ma" to vocalize. But there are ways. Many people mourned the passing of Apple innovator Steve Jobs, and many others scorned the mourning. I mourn Steve Jobs for what he and his company have done for assistive

technology. There is no glory in assistive technology like there is in other kinds of sleek development sectors, but Apple as a company has done more for alternative communication methods than anyone realizes. In my life, the strength of the iTouch and the iPad doesn't lie in Angry Birds, or mobile Facebook. It lies in apps like Proloquo2Go, which enable Caroline to use an iPad as a communication device.¹ It lets her tell us what kind of food she wants to eat, whether she's tired, whether she wants a hug. Basic things that she cannot verbalize. Things that are a logistical nightmare and endlessly frustrating for people facing similar issues that Caroline does, when you're stuck with paper and Velcro communication boards.

¹ Photo Courtesy: <http://katilea.wordpress.com/about/proloquo2go-and-ipad/>

The people who care about those with I/DD, and I/DD advocates themselves are making huge waves, but silently. Why do we all work so passionately but so silently on something that affects so very many people?

SITUATION ANALYSIS

The outlook for most things affected by our slowed economy seems bleak, but it is especially so for individuals with I/DD and their families and caretakers.

When President John F. Kennedy took office in 1961, he created a panel to bring attention the dire needs of people with intellectual and developmental disabilities (I/DD) that had for most of the history of the United States up until that moment been a private struggle for families. He called into mainstream recognition major issues facing people with I/DD in the '60s—deplorable living conditions in institutions, limited educational and employment opportunities, etc. He set into action a chain of events that led to the enactment of major pieces of legislation— the Individuals with Disabilities Education Act of 1990 (amended in 2004, and preceded by the Education for All Handicapped Children's Act of 1975) the Americans with Disabilities Act of 1990, the Affordable Care Act of 2010, Rosa's Law of 2010, and many more.

In the first half of the twentieth century, huge shifts in public thinking and attitudes toward people with I/DD occurred. From the late 19th-century to the early 20th, the American public was terrified by the “menace of the feeble-minded.”² This popular, fearful sentiment made this period one of the most hostile in our country's history toward people with I/DD. There was little consistency in the labels used to describe the I/DD population of the time. “Feeble-minded” was a catchall term to describe people with I/DD in the early 20th century.³ Later, ‘feeble-minded,’ ‘mental defective,’ and ‘mentally deficient’ were used interchangeably with little regard for a close consideration of a definition of each.⁴

² Grossberg, Michael. "From Feeble-Minded to Mentally Retarded: Child Protection and the Changing Place of Disabled Children in the Mid-Twentieth Century United States." *Paedagogica Historica* 47, no. 6 (2011): 729-47.

³ Noll, Steven. *Feeble-Minded in Our Midst: Institutions for the Mentally Retarded in the South, 1900-1940*: University of

The eugenics movement, or the science of improving a human population by controlled reproduction to increase the occurrence of more desirable genetic characteristics, strongly promoted the sterilization of those with I/DD. Proponents argued that the needs of society must be considered over the needs of dangerous, “hereditarily unfit” individuals.⁵ They also advocated sterilization as a “children’s right”—the right to be “well born.”⁶ In 1920, the Supreme Court upheld the sterilization of an 18-year-old girl by affirming that society had the right to “prevent those who are manifestly unfit from continuing their kind.”⁷ In the years after the ruling was handed down, half of states enacted sterilization laws before the ruling was overturned in 1942.

The medical model of disability, created in the late nineteenth century, “personalizes disability, casting it as a deficit located within individuals that requires rehabilitation to correct the physiological defect or amend the social deficiency.”⁸ The medical model promoted the perception of disability as an individual failing, and the “primary source of a disabled person’s identity.”⁹

Ignoring the content of the public conversation about intellectual and developmental disabilities momentarily, it is important to note that the conversation was increasingly leaving the private sphere and entering the public sphere. The late 40s and 50s saw many published “confessionals” that slightly opened the conversation about I/DD. Notable public figures like Pearl Buck, winner of the Nobel Prize in Literature, and movie and television stars of the era, Dale Evans and Roy Rogers, published such confessionals. These stories discussed parents’ decisions to (or to not) institutionalize their children, the challenges of

North Carolina Press Chapel Hill and London, 1995.

⁴ Ibid.

⁵ Grossberg, Michael. "From Feeble-Minded to Mentally Retarded: Child Protection and the Changing Place of Disabled Children in the Mid-Twentieth Century United States." *Paedagogica Historica* 47, no. 6 (2011): 729-47.

⁶ Ibid.

⁷ Ibid.

⁸ Ibid.

⁹ Ibid.

daily life, societal pressures, etc. Although the parents altogether had no resounding, unified message, the very public act of publishing these stories noted a shift from private shame, to public discussion.

It was at this point that parents began to organize; they demanded more aid for their families while working to “overcome the shame and isolation of having ‘retarded’ children in their families.”¹⁰ They began to more actively mobilize to influence both public opinion and public policy.¹¹ These fledgling advocacy groups also aimed to reframe the issues—problems did not stem only from their child’s literal disabilities, but also from the way society and the government approached the I/DD community.

Since this particularly agitated period, especially in the later 20th century, there have undeniably been many victories for people with I/DD, including drastically decreasing the number of people who live in institutions, who instead now live in the community with family members or in group homes, etc., the legislative victories won that entitle people with I/DD to a full and appropriate education through the public school system, and the slow progress of people with I/DD into the workforce.

There are still changes to be made, and much of the legislation already enacted still needs to be fully realized; the quality of education needs to continue to improve rather than languish, employment discrimination is still a huge problem, the subminimum wage (the practice of obtaining special legal exemption from paying people with I/DD the full minimum wage) needs to be abolished, etc.

There is a whole generation of young adults and siblings that needs to be educated and impassioned to action. These will soon be our issues, not just our parents’.

¹⁰ Ibid.

¹¹ Ibid.

BRIEF OVERVIEW OF MAJOR ISSUE AREAS

Crime and Sexual Abuse

The national crime victimization survey released in October 2011 found that people with disabilities are victims of violent crime at a rate that is double that of people without disabilities. People with cognitive disabilities were most likely to experience crime compared to people with other kinds of disabilities. Women with cognitive disabilities were slightly more likely than men to be victimized.¹²

Although elevated sexual abuse rates of women with disabilities has long been known, a recent study in the American Journal of Preventative Medicine found that men with special needs are at an especially high risk as well—they are almost four times more likely to experience sexual abuse than men without disabilities.¹³

Education

Although the Individuals with Disabilities Education Act (IDEA) requires that students with disabilities are entitled to an education to the maximum extent possible with students without disabilities. Despite this, many students with I/DD are relegated to contained special education classrooms, or even in separate schools, with inadequate opportunities to participate academically and socially in ‘mainstream’ or ‘general education’ classrooms and general school activities.¹⁴ Often, especially with recent budget cuts, many

¹² Heasley, Shaun. "Crime Odds Nearly Double for People with Disabilities." *Disability Scoop* (October 13, 2011a), <http://www.disabilityscoop.com/2011/10/13/crime-odds-disabilities/14230/>.

¹³ Diamant, Michelle. "Men with Disabilities at 'Heightened Risk' of Sex Abuse." *Disability Scoop* (October 11, 2011a), <http://www.disabilityscoop.com/2011/10/11/men-sex-abuse/14219/>.

¹⁴ The Arc of the United States, Congress of Delegates. "Life in the Community: Education." The Arc of the United States, 2008. <http://www.thearc.org/page.aspx?pid=2368>.

schools lack both a sufficient number of educators, and/or educators who are sufficiently trained to provide the appropriate guaranteed education.

The Council for Exceptional Children, an organization for special educators, conducted a poll of 701 special education administrators from 45 states, and found that overwhelmingly, nearly all reported they are currently experiencing, or expect to soon experience an “increased strain on the availability of services” for students with disabilities.¹⁵ Over 90% said they anticipate taking on more students with fewer budgets and smaller resources.¹⁶

The FINDS Survey, conducted by The Arc of the United States, found that 52% of families reported that their family member with I/DD left school without receiving a high school diploma, and only 8% report having any college experience.¹⁷ Fewer than one-third of students with I/DD are reported as fully included in regular classrooms in regular schools in primary, middle, or high school.¹⁸ Only 60% of parents are satisfied with the quality of education provided to their child with I/DD in primary, middle, or high school.¹⁹

Discrimination / Employment / Sheltered Workshops

In a time where the job economy is still having trouble recovering, the unemployment rate among the general population, as of October 2011, was 9.1 percent. The unemployment rate, in contrast, of Americans with disabilities remains above 16%.²⁰

In the FINDS survey, 85% of families reported that their adult family member with I/DD was not employed either part-time or full-time.²¹ Of those 15% who were employed in

¹⁵ Diamant, Michelle. "Special Education Hard Hit by Economy." *Disability Scoop* (April 5, 2011c), <http://www.disabilityscoop.com/2011/04/05/sped-economy-poll/12797/>.

¹⁶ Ibid.

¹⁷ "Still in the Shadows with Their Future Uncertain: A Report on Family and Individual Needs for Disability Supports (Finds)." The Arc of the United States, June 2011.

¹⁸ Ibid.

¹⁹ Ibid.

²⁰ Heasley, Shaun. "Job Woes Linger for Those with Disabilities." *Disability Scoop* (October 7, 2011b), <http://www.disabilityscoop.com/2011/10/07/september-11-jobs/14193/>.

some form, a majority (54%) still work in sheltered workshops and enclave settings; only 57% report earning at least minimum wage.²² A new measure recently introduced in early October 2011 in the U.S. House of Representatives would phase out the practice of allowing employers to pay workers with disabilities a subminimum wage.²³

This is an issue connected to education—IDEA, at least technically, guaranteed students with disabilities an education to the maximum extent possible, but there is no system in place to for continued support from school-to-community.

Housing (Group Homes / Institutionalization)

Today, there are 7-8 million people with I/DD living in the United States. Conservative estimates say that 1.25 million of those are children.

In 1967, there were more than 187,000 people with I/DD living in state institutions. By 2009, that number was reduced to less than 34,000.²⁴ 98% of people with I/DD now live in the community—78% with family members, 9% in group-homes of six or fewer people, and 7% in their own homes or apartments.²⁵

Health Care / Services & Supports

58% of parents/caregivers report spending more than 40 hours per week providing support for their loved one with I/DD, including 40% spending more than 80 hours a week.²⁶

²¹ "Still in the Shadows with Their Future Uncertain: A Report on Family and Individual Needs for Disability Supports (Finds)." The Arc of the United States, June 2011.

²² Ibid.

²³ Diamant, Michelle. "Congressmen Call for End to Subminimum Wage." *Disability Scoop* (October 5, 2011b), <http://www.disabilityscoop.com/2011/10/05/congressmen-end-subminimum/14181/>.

²⁴ American Association on Intellectual and Developmental Disabilities. "Definition of Intellectual Disability." http://www.aaid.org/content_100.cfm?navID=21.

²⁵ "Still in the Shadows with Their Future Uncertain: A Report on Family and Individual Needs for Disability Supports (Finds)." The Arc of the United States, June 2011.

²⁶ Ibid.

For many, family efforts have been supplemented by some government-funded programs and services delivered through school systems and state agencies through Medicaid that support a complex network of community-based nonprofits and for-profit service providers, but appropriate, adequate, and affordable supports and services are getting harder to find.²⁷ More than 75% of families report being unable to find essential supports and services (like afterschool care, non-institutional community services, trained, reliable home-care providers, summer care, residential, respite and other services).²⁸

Most distressing is the state of waiting lists: one-third of parents and caregivers report being on waiting lists for government-funded services, with the average wait being more than five years. This care structure is becoming more and more unstable, with the more than 700,000 people with I/DD living with caretakers who are 60 years or older.²⁹

Current legislation in the U.S. House of Representatives threatens to cut more than \$770 billion over the next ten years from Medicaid, which provides the majority of funding for services for people with I/DD (while also capping future expenditures) and cut an “additional \$2.1 trillion dollars from Medicare, low-income housing, education funding, food stamps and other programs of importance to low and moderate-income families, including people with I/DD.”³⁰

²⁷ Ibid.

²⁸ Ibid.

²⁹ Braddock, D., Hemp, R & Rizzolo, M.C. "The State of the States in Developmental Disabilities: 2008." American Association on Intellectual and Developmental Disabilities, 2008.

³⁰ "Still in the Shadows with Their Future Uncertain: A Report on Family and Individual Needs for Disability Supports (Finds)." The Arc of the United States, June 2011.

AS IT STANDS...

As mentioned previously, issues facing people with I/DD and their families and caretakers are not trendy; it's not a "sexy" issue. It's a much more silent issue, often relegated to the shadows, but no less important than explosive, visible issues like racial equality, gender equality, cancer research, and most recently the issues brought into mainstream discussion by the Occupy movement—student loan debt, tax equality, outrageously disproportionate pay, etc. The main difference is that on all of those issues, most of the people affected can advocate on their own behalf. A growing number of self-advocates with I/DD are becoming empowered to enact change, especially in the Autism community, but many cannot. Some, like Caroline, literally don't have the intellectual capacity to understand what Medicaid cuts mean, etc., and for a long time, that has meant that families and caretakers fight just to operate within a constantly shrinking system of governmental supports, and nonprofit network, rather than pushing for larger, systematic change. With the weight of these financial and caretaking responsibilities, many overburdened people cannot find the energy or time to raise their voices for the benefit of their loved one, who oftentimes, like Caroline, are unable to raise that voice for themselves.

What this particularly means is that, as mentioned before, both an entire generation of people with I/DD are going to outlive their lifelong caretakers, and a generation of young adults is about to inherit an enormous issue that has been neglected following a period of victories that followed President John F. Kennedy. We have been silent when we need to raise our voices.

CASE ANALYSIS: THE GIVE A DAMN CAMPAIGN

The Give a Damn campaign is a project of the True Colors Fund, founded by Cyndi Lauper, and launched in April 2010. The campaign's goals are 1) to increase awareness and knowledge of issues in the LGBT community, and 2) to engage people in activism. In sum, the goal is to achieve equality for all through informing people, especially straight allies, and motivating them to become involved in the movement.

Fueled by the idea that equality can be achieved through open sharing of knowledge and information, Give A Damn aims to be a go-to resource that informs all people—straight and LGBT, about issues facing the LGBT community. The campaign's main tactics are public service announcements and packaged online content.

The campaign launched with a public service announcement that featured several notable public figures identifying their sexuality calling the public to action. Anna Paquin, a main character in the hit HBO show *True Blood*, publicly announced for the first time that she identifies as bisexual. The attention that followed the premiere of the PSA crashed the Give a Damn website.

Give a Damn gets most of its mainstream exposure from PSAs, also made available online. Since the launch, the campaign has generated additional issue-specific PSAs; there are videos to target homelessness, suicide, hate crimes, and others.

The campaign's taglines are individualized variations on the "Give a Damn" campaign name: "We give a damn, do you?" "Do you give a damn?" and several others. Featured celebrities have included actor Susan Sarandon, actor Alan Cumming, musician Pete Wentz, celebrity Sharon Osborne, musician Elton John, musician Jason Mraz, actor Cynthia Nixon, celebrity Kim Kardashian, actor Anna Paquin, and many others.

The campaign website provides a variety of informational resources. It has a "Damn Issues" section, which features summaries about workplace discrimination, hate crimes, military, marriage, youth and school, youth and suicide, youth and homelessness, older adults, faith, parenting, health care and immigration. The site encourages visitors to get informed, and then calls them to share that information with people in their lives. The "Personal Stories" section encourages visitors to share their personal experiences with the

different issues highlighted in the issues section. The “Damn Blog” aggregates equality news. The campaign also has an active presence on Facebook, Twitter and Youtube.

The campaign has seen success in the year and a half since it’s spring 2010 launch; the campaign has over 124,000 ‘likes’ on Facebook, the Youtube channel has nearly 1,329,000 views, and @wegiveadamn has 19,500 followers on Twitter. Nearly 87,500 people have joined the campaign directly.

The campaign is buffered largely by its star power—Cindy Lauper calls in her celebrity connections and her own celebrity to promote the campaign. It achieves its goal of acting as a resource center that generates rich content about the topic.

RESEARCH

I conducted this informal study to enlighten my background research upon which to create my campaign design. The purpose of the study was to discover general trends of young adults' awareness and knowledge of what "intellectual and developmental disabilities" means, and attitudes towards those with I/DD. I created and executed an online survey of 261 young adults to produce the conclusions below.

The research was conducted to provide answers for 4 research objectives:

1. What is the existing awareness in the target audience of the prevalence of people with I/DD?
2. How personally affected does the target audience feel in their personal lives by people with I/DD?
3. How motivated is the target audience already to be active (volunteer/advocate) in this particular area?
4. Is the target audience interested in learning more about the topic? If so, what specific topics are they most interested in?

Key Findings:

- There is already a good base of awareness.
- There is potential to call more people to action.
- The target audience is interested in learning more.

RESEARCH METHODOLOGY

Secondary Research:

I decided to focus my research on existing literature about public attitudes, especially student attitudes, toward people with I/DD. Attitudes are enduring evaluative predispositions "acquired through subtle interpersonal influence processes."³¹ (Rillotta &

³¹ Rillotta, Fiona; Nettelbeck, Ted. "Effects of an Awareness Program on Attitudes of Students without an

Nettelbeck, 2007) Attitudes are learned, and therefore subject to change depending on the environment and the quality of information available. Education and increased contact, specifically positive contact, can accomplish long-term attitudinal and behavioral change; therefore, more contact between students with and without disabilities should result in changed (more positive) attitudes that further social acceptance. The theory of persuasive communication suggests that, in order to change attitudes an individual must be *repeatedly* presented with new information.³² (Rillotta & Nettelbeck, 2007) In order to break down social barriers, therefore, it is important to find a way to provide people without disabilities with opportunities for interaction, and access to information about and familiarization with I/DD. One study not only found supporting evidence (further supporting an already-well-supported theory) that more information about and exposure to people with I/DD is associated with more positive attitudes, but also that the attitudes of those who been involved with an awareness program 8 years prior were just as favorable as those of the students who had just completed a similar program, suggesting longevity in the effects of exposure to such a program.³³ (Rillotta & Nettelbeck, 2007) In general, however, there is a lack of evidence to support this finding, because there is a lack of focus on the subject of long-term attitudinal change.³⁴ (Ouelette-Kuntz, Burge, Brown, Arsenault, 2010)

Although the huge movement toward deinstitutionalization has resulted in the physical movement of individuals with I/DD into the larger community, physical integration does not necessarily guarantee social inclusion.³⁵ (Ouelette-Kuntz, Burge, Brown, Arsenault, 2010) Social distance was first defined by Bogardus as the ‘degree of sympathetic understanding between individuals or groups’ and also differentiated that physical proximity is inadequate in measuring the closeness between people. One study found that prior knowledge of a person with I/DD predicted attitudes reflecting less social distance, and children in schools that foster an environment with greater contact between those with and without disabilities express less social distance than children in less integrated schools.³⁶ (Ouelette-Kuntz, Burge, Brown, Arsenault, 2010) It also found that participants who

Intellectual Disability Towards Persons with an Intellectual Disability." *Journal of Intellectual & Developmental Disability* 32, no. 1 (March 2007): 19-27.

³² Ibid.

³³ Ibid.

³⁴ Helene Ouelette-Kuntz; Philip Burge; Hilary K. Brown; Elizabeth Arsenault. "Public Attitudes Towards Individuals with Intellectual Disabilities as Measured by the Concept of Social Distance " *Journal of Applied Research in Intellectual Disabilities* 23 (2010): 132.

³⁵ Ibid.

³⁶ Ibid.

perceived the level of disability affecting most individuals with I/DD to be mild, rather than moderate or even severe, were “less likely to express a wish for social distance between themselves and individuals with intellectual disability.” This finding parallels similar findings in mental illness research, where participants tend to prefer greater social distance from individuals with ‘severe’ mental illnesses, as opposed to ‘mild’ mental illness. A few studies suggest that people’s reluctance to interact with people with I/DD may be due in some capacity to “discomfort and anxiety.”³⁷ (Ouelette-Kuntz, Burge, Brown, Arsenault, 2010)

A review study shed light on a larger picture that emerges from the synthesis of the findings of 75 surveys concerning public awareness, attitudes and beliefs regarding intellectual disability. On an optimistic note, overall public attitudes largely skew positively toward inclusion. On the other hand, most comparative studies of attitudes examining the social interactions of members of different peer groups found that as a social group, people with I/DD “consistently emerge as one of the least desirable groups.” Also, the general public appears to hold more negative attitudes towards individuals with ‘severe,’ rather than ‘mild’ intellectual disabilities. The study also linked negative attitudes to misconceptions about the capabilities of people with intellectual disabilities.³⁸ (Ouelette-Kuntz, Burge, Brown, Arsenault, 2010) For example, one given misconception is that most people with I/DD have severe disabilities; most people who recognize that most intellectual disabilities are mild show lower social distance toward the I/DD community as a social group.

Very little of the available literature specifically addresses the question of the level of existing public knowledge about I/DD. The available studies “suggest that the public generally has a limited understanding of the concept of ‘intellectual disability’, is confused about different terminology used and that awareness varies considerably across cultures, but is generally low.”³⁹ (Ouelette-Kuntz, Burge, Brown, Arsenault, 2010)

So it is very effectively established that contact, especially positive contact, has been shown to be associated with more positive attitudes. The main method of achieving this contact is usually through school programs that place importance on interaction between peers with and without disabilities and through inclusive education. However, there has been little research to evaluate the effectiveness of this method. There are very few efforts to evaluate

³⁷ Ibid.

³⁸ Ibid.

³⁹ Ibid.

the methods already widely in place to tackle low awareness and negative attitudes in the general public.⁴⁰ (Ouelette-Kuntz, Burge, Brown, Arsenault, 2010)

Quantitative and Qualitative Research:

- One web survey was conducted utilizing Survey Monkey and 261 responses were gathered and analyzed. The questions for the final survey were pre-tested for usability by in the target audience before being implemented.
- The sampling method was a convenient sample, and invitations to take the survey were sent out via Facebook. A convenient sample is a non-random sample taken from a list of people known by the researchers. While the sample provides helpful information it cannot be generalized and the margin of error cannot be calculated. Efforts were made to get responses from as wide a variety of people falling within the target age range as possible. Responses were gathered between October 26 and October 30, 2011. Analysis of the survey results was conducted through Survey Monkey.

Research Limitations:

- Assumptions
 - Responses may have been altered to reflect a more positive attitude toward people with I/DD, and a less positive attitude toward casual use of the word “retarded” because the content of the survey focused on people with I/DD and the usage of the word “retarded.”
- Limitations
 - While the results provide useful insight, the sampling method used was a convenient sample, and therefore cannot be generalized; the margin of error cannot be calculated.
 - Females were overrepresented.
 - During the course of analyzing, the school’s premium Survey Monkey account expired, so aside from what I had already looked at, I only had access to the first 100 responses. Only data pulled from before the expiration was used.

⁴⁰ Ibid.

FINDINGS:

Research Question #1: What is the existing awareness in the target audience of the prevalence of people with I/DD?

- 84% of respondents were not familiar with the acronym “I/DD”.
- 70% of respondents were familiar with the term “intellectual and developmental disabilities.”
 - Of the 70% who were familiar, 71.8% responded that they were completely comfortable or comfortable enough with explaining “intellectual and developmental disabilities” to someone else.

Research Question #2: How personally affected do members of the target audience feel in their personal lives by people with I/DD?

- A majority of people know someone in some capacity with I/DD
 - 6.6% had an immediate family member
 - 28.3% had an extended family member
 - 40.7% responded that they had a friend
 - 24% knew someone with I/DD through a program (like Best Buddies or Special Olympics)
 - 10.5% responded that they knew someone with I/DD through another means

Research Question #3: How motivated is the target audience already to be active (volunteer/advocate) in this particular area?

- 35.9% of respondents had previously volunteered for a program that works with people with I/DD
- Of those who answered ‘yes’ to having volunteered for a program that supports people with I/DD, 42% said they felt they have been involved or highly involved in advocating for people with I/DD.
 - 39.8% responded ‘neutral’

Research Question #4: Is the target audience interested in learning more about the topic? If so, what specific topics are they most interested in?

- 70% of respondents responded that they would be interested in learning more about issues in the I/DD community. 8.7% responded that they would be extremely interested.

THE CAMPAIGN: USE YOUR WORDS

I propose to launch an awareness campaign designed to solve the identified problems: increase awareness in the general public, engage that audience to act on that awareness, and motivate siblings to become more active, vocal advocates.

The name I have chosen as a campaign name, “Use Your Words,” means several different things; first, that an action needs to happen, and second, that the basic focus is communication. My family always called Caroline’s augmentative communication device her ‘words.’ For example, if she was upset about something, we would try to figure it out by giving her the device and saying, “Use your words!” On a plane recently I sat by a woman with a small child—when coping with a tantrum, the woman used the same phrase, “Use your words.” Communication (or “words”) takes many different forms, and by extension, ability takes different forms as well, and this phrase as a campaign name aims to open that line of thinking.

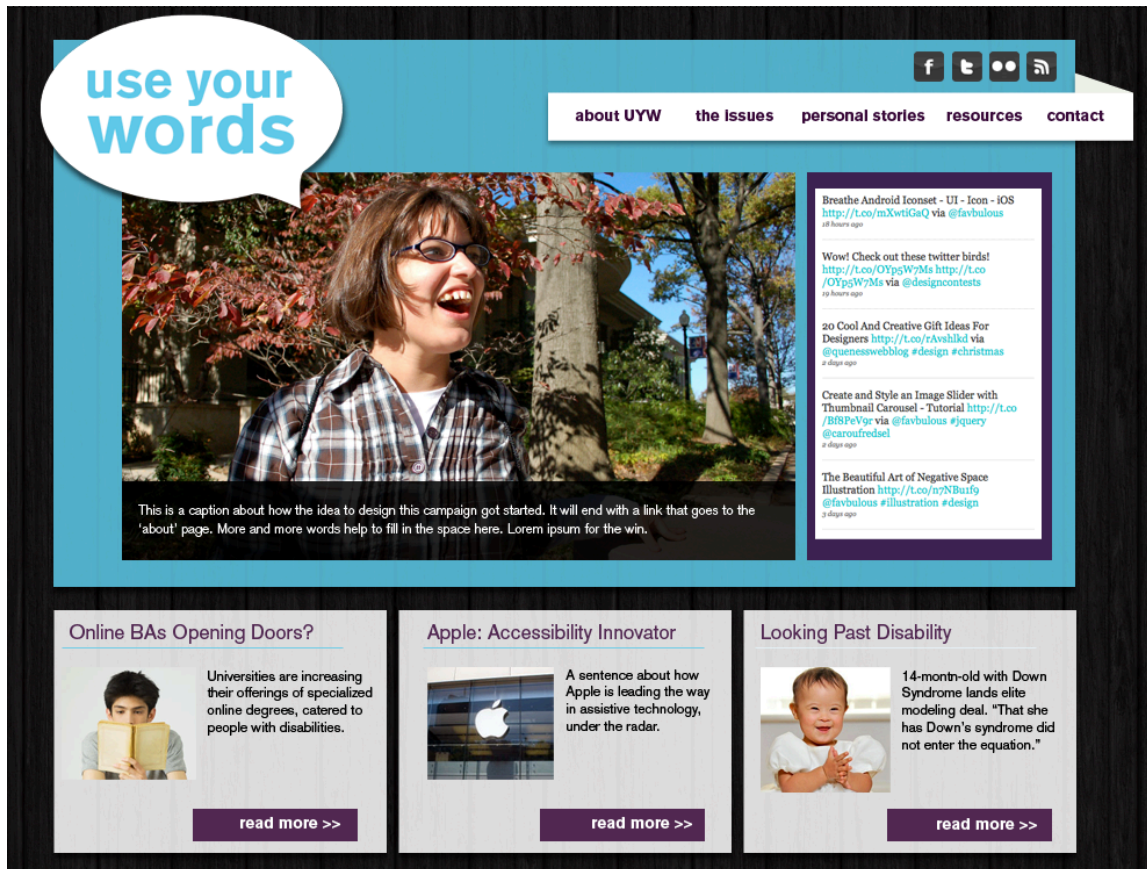
Function as an Informational Resource

A primarily web-based, go-to resource, especially for people who are unfamiliar with the I/DD community and I/DD issues.

- This campaign is based on the idea that through increasing awareness and positive contact, the general public will be less fearful and anxious about interacting with people with I/DD.
- The campaign will in part serve as an informational resource hub, conveyed in a friendly tone, with casual language; Many people can feel embarrassed of their lack of knowledge of and anxiety toward people with I/DD—the campaign will invite them to ask questions and learn more.

Planned Campaign Elements

- Campaign Site
 - The campaign site will be the central location of all campaign resources and multimedia.
 - Potential Design:



- Informational Pages
 - A glossary of influential legislation
 - A concise summary of the history of public sentiment and public policy toward people with I/DD
 - Informational issue sections: Concise summaries of major issue areas in the I/DD community.
 - Education
 - Employment
 - Family Support
 - Health Care

- Housing
 - Transportation
 - Causes
 - Prevention
 - Abuse
 - Current Research
- Campaign Blog
 - A blog, connected but separate from the main site, reacting to news and current events affecting the I/DD community.
- Videos
 - Personal feature videos of people with I/DD, their siblings or other family members, or friends of the I/DD community discussing reactions to current events and personal stories.
- Volunteer & Services Network
 - A directory of the network of:
 - Organizations that work on I/DD policy issues
 - Organizations to get involved with as a volunteer or transitioning into a nonprofit career in the field.
- Social Media Presence
 - Establish a comprehensive, active social media presence to work in concert and help populate rich content on the website with the following platforms:
 - Facebook
 - Google Plus
 - Twitter
 - YouTube
 - Flickr

Objective(s)

- To increase awareness and knowledge in the general public of issues and terminology specific to the I/DD community
- To engage people to become involved as a volunteer

Target Audience

- Primary: Young adults (ages 18-29) with a direct connection to the I/DD world as a sibling or immediate family member.
- Secondary: Young adults (ages 18-29) with no direct connection to the I/DD world

Strategy

- Engage and inform the target audience by packaging dense, inaccessible information and terms into various kinds of digestible, informational multimedia pieces.

Key Messages

1. People with I/DD have a voice, and their identities are not rooted in disability.
2. In general there are many misconceptions about I/DD, and actively learning more about the issues will increase social acceptance and understanding.

APPENDIX – Survey Design

You have a **BASIC account** | To remove the limits of a BASIC account and get unlimited questions, [upgrade now!](#)

Capstone - I/DD Survey [Edit](#)

Design Survey

Collect Responses

Analyze Results

Edit Survey

Preview Survey

Send Survey »

To change the **look** of your survey, select a theme below.

Aqua

Create Custom Theme

+ Add Page

PAGE 1

Edit Page Options ▼

Add Page Logic

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Show this page only

+ Add Question ▼

Edit Question ▼

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As part of my research for my capstone project, I am surveying young adults (18-29) about their knowledge of certain kinds of disabilities. Your opinions are important to the accuracy of this survey and I appreciate both your help and your complete honesty. This survey will take less than ten minutes and your answers will remain completely confidential. Thank you very much for your help!

+ Add Question ▼

+ Add Page

PAGE 2

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+ Add Question ▼

Q1

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*** 1. With what gender do you identify?**

Female

Male

+ Add Question ▼

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Q2

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*2. What is your age?

17 and younger

18-20

21-24

25-29

30+

+ Add Question ▼

+ Add Page

PAGE 3

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+ Add Question ▼

Q3

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*3. Do you know what the acronym "I/DD" stands for?

Yes

No

+ Add Question ▼

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PAGE 4

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+ Add Question ▼

Edit Question ▼MoveCopyDelete

"I/DD" stands for intellectual and developmental disabilities.

+ Add Question ▼Split Page Here

Q4 Edit Question ▼Edit Question Logic (3)MoveCopyDelete

4. Have you ever before heard the term "intellectual and developmental disabilities?"

Yes

No

Maybe

+ Add Question ▼

+ Add Page

+ Add Question ▼

Q5 Edit Question ▼Add Question LogicMoveCopyDelete

5. How comfortable would you feel explaining to someone what the term "intellectual and developmental disabilities" means?

Completely comfortable

Comfortable enough

Uncomfortable

Extremely uncomfortable

+ Add Question ▼

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[Show this page only](#)[+ Add Question](#) ▼**Q6**

Edit Question ▼

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6. Examples of I/DD include, but are absolutely not limited to: Autism, Down Syndrome, Fragile X, cerebral palsy, and Fetal Alcohol Syndrome. Do you know someone with intellectual and/or developmental disabilities? Please check all that apply:

Yes – immediate family member

Yes – extended family member

Yes – friend

Yes – through a program (ex. Special Olympics, Best Buddies)

No

Don't know

Yes - Other (please specify)

[+ Add Question](#) ▼[Split Page Here](#)**Q7**

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7. Are you a sibling of a person with I/DD?

Yes

No

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[+ Add Question](#) ▼**Q8**[Edit Question](#) ▼[Edit Question Logic \(3\)](#)[Move](#)[Copy](#)[Delete](#)

8. Have you ever volunteered for a program that supports people with I/DD? (Ex. volunteered in a special education classroom, been involved with Best Buddies or Special Olympics, etc)

No

Don't Know

Yes (please specify)

[+ Add Question](#) ▼[+ Add Page](#)**PAGE 8**[Edit Page Options](#) ▼[Add Page Logic](#)[Move](#)[Copy](#)[Delete](#)[Show this page only](#)[+ Add Question](#) ▼**Q9**[Edit Question](#) ▼[Add Question Logic](#)[Move](#)[Copy](#)[Delete](#)

9. How involved would you say you have been in volunteering/advocating for people with I/DD?

Highly involved

Involved

Neutral

Uninvolved

Don't know

[+ Add Question](#) ▼[+ Add Page](#)**PAGE 9**[Edit Page Options](#) ▼[Add Page Logic](#)[Move](#)[Copy](#)[Delete](#)[Show this page only](#)

+ Add Question ▼

Q10

Edit Question ▼Add Question LogicMoveCopyDelete

10. If you are speaking to someone who uses the word ‘retarded’ in casual conversation, does it make you uncomfortable, or is it not a big deal?

Extremely uncomfortable

A little bit uncomfortable

Not really a big deal

Not at all a big deal

+ Add Question ▼Split Page Here

Q11

Edit Question ▼Add Question LogicMoveCopyDelete

11. Do you use the word ‘retarded’ in casual conversation?

Frequently

Maybe sometimes

Never

Don't know

+ Add Question ▼

+ Add Page

PAGE 10

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+ Add Question ▼

6 of 10

12/13/11 11:35 AM

Q12 Edit Question ▼ Add Question Logic Move Copy Delete**12. Do you think of the word 'retarded' as hurtful, or just an expression?**☐ Hurtful☐ Just an expression☐ Other (please specify)[+ Add Question](#) ▼ [Split Page Here](#)**Q13** Edit Question ▼ Add Question Logic Move Copy Delete**13. If you are speaking to someone who uses the word 'retarded' in casual conversation, how likely are you to say something to them about it?**☐ Extremely likely☐ Maybe sometimes☐ Probably not☐ Definitely not☐ I don't know[+ Add Question](#) ▼[+ Add Page](#)**PAGE 11** Edit Page Options ▼ Add Page Logic Move Copy Delete[Show this page only](#)[+ Add Question](#) ▼**Q14** Edit Question ▼ Add Question Logic Move Copy Delete**14. How interested would you be in learning more about issues in the I/DD community?**☐ Extremely interested☐ Interested☐ Disinterested☐ Extremely disinterested

+ Add Question ▼

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Q15

Edit Question ▼

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15. What issues would you be interested in learning more about specifically? (check all that apply)

Education

Employment

Family Support

Health Care

Housing

Transportation

Causes

Prevention

Abuse

Current Research

Other (please specify)

+ Add Question ▼

+ Add Page

PAGE 12

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+ Add Question ▼

Q16

Edit Question ▼

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16. If you'd like, please write anything — a personal story, about your involvement, etc. that you feel inclined to share. (Anything that you would want other people to know about your personal experience with someone with intellectual/developmental disabilities.)

+ Add Question ▼

+ Add Page

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Edit Question ▼MoveCopyDelete

Thank you so much! If you'd like to see the results of this survey when it is complete, please email me at ar5457a@student.american.edu.

Also, if you are a sibling/family member/friend/etc. of a person with I/DD, and would be interested in helping me with my project by sharing your story (very minor time commitment!) please let me know by the same email!

I appreciate you taking the time out of your day! Have a good one.

+ Add Question ▼Split Page Here

Edit Question ▼MoveCopyDelete

[+ Add Question ▼](#)[+ Add Page](#)[Back to My Surveys](#)[Preview Survey](#)[Send Survey »](#)

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