5-2017

Disability: Becoming an Advocate for Persons with Disabilities and Understanding the History of the Disability Movement in the United States

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Recommended Citation

Ramsay, Frances Mason, "Disability: Becoming an Advocate for Persons with Disabilities and Understanding the History of the Disability Movement in the United States" (2017). *Senior Theses*. 196.
https://scholarcommons.sc.edu/senior_theses/196

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I. Summary

I knew I wanted focus on disability, specifically disability among children, for my Senior Thesis, because of the time that I spent with these children growing up, in high school as a Special Olympics coach, and over the past two summers at a camp for children with disabilities and chronic illnesses. Beyond that, I knew I wanted to, if possible, incorporate stories and images from the families that I have known so they could express their own thoughts on the topic. I wanted to "create a face" for the history and literature included in the paper, to make it more than just research. As the paper began to take shape last semester, I decided to divide my paper into five major sections or topics: "Disability Legislation", "Disability in the Education System", "Disability Activism", "Disability Services", and "Caring for a Child with Disabilities." It is important to note that the terms "handicapped" and "retarded" were used as descriptors for persons with disabilities when educational and legislative changes were first introduced; these terms have been retained when used in this document solely for the purpose of historical accuracy. It is also important to know that any stories or photographs included throughout the paper are done with the consent of the child and/or their legal guardian.

The first section, "Disability Legislation," reads as a timeline of the history of all things related to disability such as acts and laws passed. The timeline follows from the mid-1960s through the present day, and highlights the most significant pieces of legislation that have been developed in these past few decades. In researching and writing this section, I learned just how many events are part of this fifty-year timeline, and how long-lasting the efforts of the original activists have become. Following this section is "Disability in the Education System," where I highlight some of the options for families when looking into where to send their child with disabilities to school. Within these school systems, a child can have a variety of different options for their specific education program, due to the use of IEPs, or Individual Education Plans. This section highlights experiences of a middle school student and her mother about with the education system in their county. I also look at the idea of the interactions between disability and other issues in the classroom, such as socioeconomic status and race. The third section is "Disability Activism," where I include different examples of activists and advocates throughout the disability movement. One significant part of this section is the inclusion of a letter to a state representative, written by a young woman in high school that I have gotten to know while working on this paper. I think that this example of activism from a child who is standing up and speaking out is so important to include, as it shows that although much work has been done in the past fifty years, there continues to be the need for advocacy around the country. Following this section is "Disability Services," which covers services ranging from federal healthcare and the challenges that families meet with this system, to mandated aids such as a wheelchair ramp at a public facility and more. For me, this section highlights just how much goes into living as a person with disabilities, and how their lives are shaped by what services are made available to them and how effective these services are. The final section of the body of the paper is "Caring for a Child with Disabilities." In this section, I highlight the role of the parent and family, as well as those who play a major role in many of these children's lives, their therapists. The paper concludes with my own reflections on where to go from here, how to continue the movement that has existed for half a century. I think it is important to look at the problems these children still face all of in order to most effectively advocate for each of them as a respectful supporter rather than someone who pities them.

II. Abstract

The purpose of this thesis is to look at the different facets that make up disability in the United States, with a specific focus on the children with disabilities. These facets include related legislation, the education system, activism, services, and what it means to care for a child with disabilities. Throughout the research process, each of these facets were analyzed to include the most significant events for the section, an overview of each section to provide insight and a small amount of background and history for someone relatively unfamiliar with the history of disability in the United States. Beyond research of documents and primary sources, stories and photographs of children with disabilities and their parents are included throughout the paper, ideally to provide insight into the day-to-day challenges faced by the families, and how they have become educated themselves to become activists for the cause. The paper concludes with my own personal reflections and the question of how the writer, the reader, and the general public are to move forward towards equalizing opportunity for the millions of children in the United States with various disabilities. As with any cause, to discontinue the push forward will only lead us a reversal of the work that has been done in the past decades, and to stop speaking and writing about the movement will lead to forgotten prejudices and disservices. The conversation must remain open and active if we are to work alongside these children for their ultimate betterment and for the betterment of those yet to come.

III. Introduction

Growing up, I was never very interested in any of my Social Studies or History classes. The names of the countries and leaders of the wars that we studied would escape me as soon as we finished the unit, and I never found myself reading about different historical events for fun as some of my peers did. The exception to this was when we learned about the Civil Rights Movement. This period always stuck out for me, and reading about those that spoke out for something they believed in, and those who risked their lives trying to escape on the Underground Railroad. I found those units so much more engaging, and therefore I learned more and wanted to continue to learn beyond the classroom. I felt the same way about a college course I took about the history of the Women's Rights Movement. The reading and lectures were interesting and learning how the movement began and why it has developed into what it is today was something I wanted to know more about.

When I began to brainstorm about what I wanted to write about for my Senior Thesis at The University of South Carolina, those with disabilities, specifically children with disabilities quickly came to mind, as I have worked with children with various disabilities at some level for more than half of my life. What I realized when I began to brainstorm was that, although I had spent so much time around these children, I knew relatively little about the history of disability in the United States, or about who paved the way for these children to receive the services and aids that they need and deserve. While we begin to learn about movements for other minority groups as early as second and third grade, persons with disabilities and the history of the Disability Movement has been left out of our history books entirely. This made me think that if I have spent so much time with individuals with disabilities and still know relatively little, how much less is the general population aware of this history, and aware of how individuals and laws have shaped what is currently available? Even further, how will individuals with no knowledge of this movement be able to join with current advocates to fight for further rights for individuals with disabilities? This lack of awareness about something that affects around fifty-six million people in our country and one billion globally was the ultimate reason I decided to write this paper. I wanted to increase my own knowledge to strive to become a better advocate- to advocate for these people and their needs, and for others to increase their own knowledge and awareness about such an important issue.

The Disability Rights Movement is one that has been around since the middle of the 20th century. People with disabilities have been stigmatized and labeled only as their disability, as may other minority groups have throughout our nation's history. The movement began because of the severe treatment of individuals with disabilities in the 1800's and well into the mid 20th century. This included anything from these individuals being objectified as an act in a circus group to being segregated from the rest of the population in an asylum or institution (*A Brief History of the Disability Rights Movement*, 2017). Since its beginning, the movement has grown in number and in its accomplishments- from the development of activist groups to the enactment of new policies. This paper offers a brief history of the major events that have unfolded in the past fifty years related to the movement, and highlights the different areas in which the Disability Rights Movement has made great strides, as well as areas in which more growth is needed.

IV. Disability Legislation

Although disabilities in various forms have existed as we know them for centuries, most legislation put in place to assist those with disability has only existed for the last fifty years. A major development on this timeline of events is the establishment of Medicare and Medicaid in

1965, two government funded programs that provide federal healthcare to Americans who are disabled and elderly, as well as for those who have lower income (*Centers for Medicare and Medicaid Services*, 2017). This legislation is still today some of the most significant that has been enacted for people with disabilities. The National Center for Law and the Handicapped, an organization dedicated to advocacy and legal support for those with disabilities, was the first of its kind when it was founded in 1971 (*Museum of Disability History*, 2014). The early 1970's were filled with court cases involving rights for disabled persons at the state level, two of the most significant being the Pennsylvania Association for Retarded Citizens V. Commonwealth of Pennsylvania (1971) and Mills v. Board of Education in Washington D.C. (1972) (*Pennsylvania Association for Retarded Citizens (PARC) v. Commonwealth of Pennsylvania*, 2016), (Katzmann, 1986). Each case pertains to legislation in relation to the education system, and will be discussed in the following section of the paper (*Disability Justice*, 2017).

As progress was being made at the district and state levels, similar work was being done by legislators and activists on the national stage. The Rehabilitation Act was passed into law on September 26th, 1973, and stands as the first federal level protection law for individuals with disabilities (*EEOC*, 2017). The Act states that "No otherwise qualified handicapped individual in the United States, as defined in section 7(6), shall, solely by reason of his [sic] handicap, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance." In the same year the American Bar Association established the Commission on the Mentally Disabled. (The name of this group changed to the Commission on Mental and Physical Disability Law in 1990 and again to Commission of Disability Rights in 2011) (*American Bar*, 2017). The purpose of the commission, to ensure lawful justice for individuals with any sort of disability, has remained the same since its establishment, and only broadened over the decades to protect and serve a wider range of disabilities. The passing of the Rehabilitation Act paved the way for progress at the national level for people with disabilities. In 1975, The Developmental Disabilities Assistance and Bill of Rights Act as well as The Community Services Act were enacted, which caused the Head Start program to increase accommodations for children with disabilities in their program (*Administration for Community Living*, 2017).

With the federal platform for basic rights established throughout the 1970's, the next decade offered opportunity to develop and pass legislation for more specific problems and areas of needed justice. Established by the United Nations, 1981 was known as the International Year of Disabled Persons, with an emphasis on nations developing organizations for people with disabilities if they did not already have such organizations in place (*United Nations*, 2017). In the United States, Alan Reich, disabled due to a diving accident, established the National Organization on Disability, an organization which today seeks to "promote the full participation and contributions of America's 57 million people with disabilities in all aspects of life" (*About*, 2017).

Several laws specific to transportation services, employment opportunity, and other accessibility services were developed and put into law during this decade, many of which will be highlighted in later sections of this paper. A significant benchmark law of this decade is the Mental Illness Bill of Rights Act, established in 1985, which focused specifically on protection and justice for persons with significant psychological disabilities (*Government Publishing Office*, 2017). Following this, in 1990, under signature of President George H. W. Bush, the Americans with Disabilities Act was put into law, a piece of legislation that is considered to be the most significant since the Rehabilitation Act of 1973 (*Americans with Disabilities Act*, 2017). A major identifier is its intent to unify organizations, advocates and allies fighting for the same cause under one act, to allow forward motion as one unit, rather than smaller organizations working independently throughout the country without a centrally defined focus.

The Americans with Disabilities legislation acted as a springboard for the progress of the decade. Legislation continued to reach beyond defined boundaries, even into the world of sports, with an Act in 1998 allow pro golfer Casey Martin to use a golf cart under the ADA in a PGA tournament, and with a 1999 ruling to allow child Ryan Taylor a spot in his local soccer league (Rothstein, 1998) (*United States Court of Appeals*, 1999). The Congressional Accountability Act of 1995 had a dual focus, and was implemented to mandate that public services, programs, and activities of the legislative branch offices accessible to people with disabilities. It also stated that congressional employees cannot be discriminated against for any form of disability (*Office of Compliance*, 2017). In 1999, the Olmstead case in which the Supreme Court upheld that "unjustified segregation of persons with disabilities" is a violation of the ADA, and that those individuals must be provided with community-based services when appropriate, reasonable, and when the community-based services are not opposed by those individuals in question (*Olmstead: Community Integration for Everyone*). This case is significant as it furthered the validity of the ADA in its purpose of serving those with disabilities and providing opportunities for equal access.

Coming into the 21st century, work is continuing to be done in terms of disability legislation, and although so many relevant laws were put into place in previous decades, a timeline of law implementation continues. The Special Olympics Sport and Empowerment Act was signed by President George W Bush, which provided funding for the expansion and continuation of the internationally known program, originally founded in 1968 (*Congress*, 2004).

A 2006 court case, United States v. Georgia established that the protection provided by the Americans with Disabilities Act (ADA) is extended into prison, preventing discrimination of inmates by prison employees because of disability (Oyez, 2017). After the death of child Jonathan Carey, who had significant autism, by a direct care worker in his school, "Jonathan's Law" was established in 2007, granting parents and guardians full access to all files related to child abuse investigation cases (*Justice Center*, 2017). In 2009, the Matthew Shephard and James Byrd, Jr. Hates Crimes Prevention Act became law, which expanded the previous definition of hate crimes to include the victim's disability (*Department of Justice*, 2015).

Even in this current decade, laws are continuing to be put into practice, some for seemingly small details that someone without disability may not even recognize as significant or necessary. In 2010, The 21st Century Communications and Video Accessibility Act was made into a law, requiring that full-length unedited programs from TV be captioned, and the captions must be available online if the program is put on the internet *(Federal Communications Commission*, 2016). This is the base of this law, with further requirements to be included in coming years. 2011 was a year for continuation of the Americans with Disabilities Act, with expansion of the law requirements to include recreational facilities and equipment such as exercise facilities and swimming pools, and also addressed problems with accessible reservations for events, hotel rooms and more (*Americans with Disabilities Act*, 2010). Under this law expansion, the term "service animal" was better defined (*Americans with Disabilities Act*, 2010). In 2013, The U.S. Department of Justice expanded the definition of disability to include an extreme food allergy. In this same year, it became law that any swimming pool identified as public or located at a place of public accommodations must meet the standards set by the ADA (*Department of Justice*, 2012). Despite numerous examples of disability-related legislation that have been enacted over the last several decades, this section covered only a select handful of key acts and laws related to disabilities.

V. Disability in the Education System

A major court case mentioned briefly in the legislation section, 1972 Mills v. Board of Education mandated that every child in the District of Columbia, regardless of severity of disability, deserved access to a free public education (Katzmann, 1986). According to the Education for all Handicapped Children Act (better known as the Individuals with Disabilities Act or IDEA), which required that all children with disabilities: a) be granted access to public education b) be provided with access to any special services as needed, and c) have a learning environment which resembles a traditional school classroom as closely as possible. Just as a Bar Commission for persons with disabilities was established, in 1978, the National Council on Disability was established as a part of the Department of Education, with a purpose of ensuring all legislation was and is upheld within the public school system (Duncan, 2009). This act protects mort than 6.5 million children in the country at the early intervention or school-aged level (*Public or Private? What each has to offer your special needs child*, 2010). Within this public school realm, a child is to be educated in the most effective classroom options for his or her specific needs. Typically, a child with disabilities will either be in a regular classroom, in a regular classroom with some kind of service provided by the school district such as an aide, or in a special education classroom at the school (Duncan, 2009). Students with disabilities receive an individualized education plan (IEP) that outlines what the best option is for this child, sometimes a combination of the above options. The IEP will include these services as well as any accommodations, materials, goals and objectives for the child, and anything else the child needs to “level the playing field” within the classroom (*Public or Private? What each has to offer your special needs child*, 2010). Ideally, the IEP is developed and revised at periodic meeting with input from parents, the student, classroom teachers, therapists (physical, occupational, speech), a psychologist, and others that the parent or school deems important to the process.

The different options for children in the public school system have been studied by scientists and different research groups not only within the United States but all over the world. Researchers Mehraban, Hasani and Amini looked at participation levels of children in schools with and without cerebral palsy (2016). In the study, they included 30 children with cerebral palsy and 30 children without cerebral palsy, ages 8 to 14 (Zadeh, Amini, and Mehraban, 2016). The children were tested while doing 55 different activities, and scored according to diversity (in the activity performed by the child), intensity (how many times they performed the activity), enjoyment, the role of others (with whom does the child perform the activities), and place (where the child performed the activity) (Zadeh, Amini, and Mehraban, 2016). The results of the study found statistically significant differences in the diversity and intensity categories, with the children with disabilities scoring lower in each category assessed (Zadeh, Amini, and Mehraban, 2016). The results also indicate that the children in the cerebral palsy group performed the skills and activities in the study much more frequently on their own rather than with their peers (Zadeh, Amini, and Mehraban, 2016). This finding is significant as the socialization of children in the school setting is important, and often the able-bodied peers lack knowledge about persons with disabilities which results in poor integration. Additionally, children frequently tutored one-on-one, or those that switch student groups throughout the day could be kept from making as many friendships as the children who stay with the same group of students all day. Regardless, this is something that needs to be better addressed as a priority within the IEP system, and determine whether isolating a child to improve his or her educational skills will lead to detriment in the long run.

If families find that their child is not successful in the public school setting, there are other options, however, most all of them are fairly expensive, which limits many families from even considering them as options. Some traditional private schools may offer programs for children with disabilities, however, as they are privately funded, they are not held to the IDEA laws and do not have to offer support to children with special needs. For those that do accept children with disabilities, parents choosing to enroll their children may be signing away the rights provided to them and their child under IDEA, as private schools are not required by law to provide necessary adaptations or services to a child with a disability (*IDEA*, 2014). There are circumstances where a child is moved from a public school setting and into a private school setting by a public agency (*IDEA*, 2014). In these cases, and in some cases where the child is moved to the private system by the parents, funding for supplemental support can be offered by the state, but the amount varies child to child, and not all children will receive funding, which would further increase the cost of the private school (*IDEA*, 2014).

Beyond traditional private schools, there are many schools in the United States that are private and designed specifically for children with disabilities. Some of these programs may even be a boarding school setting or offer year around schooling. These schools offer exceptional programs as they are not confined to meeting the public school standards, and thus can completely redesign the way that they teach their students. Many of these schools are specifically designed to work with students with a specific type of need, such as learning disabilities, visual disabilities, or cognitive disabilities (*The 50 Best Private Special Needs Schools in the United States*, 2017). For many families, this setting may be the best option, however, tuition at some of the top programs across the country is not cheap- most are well above $10,000 per year, with some programs reaching as much as $100,000 per year, a price few can afford, especially in addition to the extra costs associated with having a child with disabilities (*The 50 Best Private Special Needs Schools in the United States*, 2017).

While the child and his or her family is certainly important in the development of an appropriate educational plan for the individual child, they are just one piece of the puzzle. The educators within the school play a huge role in whether or not that child will succeed in the classroom, and therefore, the education and tools provided to teachers with special needs children in their classrooms are so important. Educators can go to school specifically to teach in a special education classroom, but those who did not go this route may still have children with an IEP in their classroom, sometimes with a personal aide, sometimes without. This is an extra challenge to the teacher in the classroom, and training is necessary to ensure that these children do not get lost in the system and fall behind in the classroom. Material available online for teachers emphasizes "creating a community," which emphasizes socialization for all students regardless of ability level, as well as "backward planning" as a successful plan to best integrate students with IEPs into the classroom (*Support and Advice for General Education Teachers on Inclusion*, 2013). The steps involved in this backward planning program involve consulting each IEP within your classroom to understand the goals for each child, both academically and behaviorally (*Support and Advice for General Education Teachers on Inclusion*, 2013). From there, a teacher should find the overlap between these personal goals and the national and state-level standards that the classroom is held to- then take these overlaps and identify where these fit into the year-long curriculum plan (*Support and Advice for General Education Teachers on Inclusion*, 2013). From there, the teacher should modify the lesson plans for each child to meet their IEP goals, create a contact list for each child to work as support as needed, such as parents, aides, and school assistants, and finally adjust lesson plans as needed to be able to accommodate all children in the classroom (*Support and Advice for General Education Teachers on Inclusion*, 2013).

If the above list to prepare for each student seems like a lot to take on as a full-time teacher with a classroom full of other students, that's because it is. At least, as someone outside of the education field, it seems like a lot to me. Particularly for new teachers or teachers who have never worked with IEP students before, I can see how this process of "creating a community" can become overwhelming and the easier option may be to send the IEP child to an exclusively special education classroom, even if the child has the potential to succeed in a traditional classroom setting.

Yet another factor that plays into a child with disabilities in the classroom is the intersection of disability and race. As Beth Ferri points out in "Tools of Exclusion," as the barriers of race and gender in schools are lowered, those barriers faced by children with disabilities seem to increase, separating children with physical and developmental disabilities from their "typical" peers more and more frequently (Ferri and Connor, 2005). Ferri also discusses the overlap of race and disability, noting that of the thirteen categories of disability, black students are disproportionally represented in nine, and are more likely than their white peers to be placed into a restrictive educational setting (Ferri and Connor, 2005). Ferri is ultimately arguing that disability in the classroom is serving as an alternate way of making or keeping classrooms racially segregated (Ferri and Connor, 2005).

With the current political changes happening in Washington, the effects are being felt by different groups of citizens across the country. The newly confirmed Secretary of Education, Betsy DeVos, has spoken out in favor of "school choice," or the development of a voucher system nationwide which would allow families to receive government scholarships towards private schools if they choose not to attend public schools (Kamenetz, 2017). Looking at this proposal specifically for children with disabilities raises several concerns that would need to be addressed if "school choice" is pushed forward in Washington. Currently, private schools do not have to adhere to the regulations put in place by IDEA. Would a private or charter school receiving vouchers have to adhere to this act? Many believe the voucher program would lead to ultimate detriment of the public school system, and as the only educational opportunity for children with disabilities to be fully supported under the law without charge, this could lead to a significant decrease in opportunities for the millions of children learning with disabilities across the country.

VI. Disability Activism

Becoming an activist and advocate for persons with disabilities, specifically children with disabilities, is so important and vital to the promotion and success of this group of individuals. As with becoming an activist for any group, there is typically some kind of event or relationship that pushes someone into this role. Maybe you become an activist when you begin to work as a pediatric orthopedic surgeon and a significant portion of your patients have disabilities. Maybe you enter the field of social work or education and begin to work closely with these children. Perhaps your child, grandchild, or sibling is diagnosed with a disability, or even you are diagnosed yourself. I think that these close relationships are most effective for becoming a true advocate; they allow for sharing of emotions and personal stories to shed light on a situation that makes people unfamiliar want to listen and learn themselves. Some of the most prominent disability activists in history took on that role because of someone in their life who impacted them. Author Jacqueline Switzer writes in “Disabled Rights” about how her knowledge of and passion for the disabled rights movement began because of her mother who had polio in her childhood, and her Ph.D. dissertation advisor who was physically disabled. These people with whom she was very close shaped how she viewed what it means to have a disability, as well as why she has paid such attention to the subject throughout her life (Switzer, 2003). Journalist Joe Shapiro recognized the importance of personal accounts in writing about this subject, and thus spent years interviewing and collecting these stories to compile in his work, “No Pity,” a read that covers a variety of topics from looking at how the Americans with Disabilities Act came to be passed, to lack of opportunity due to discomfort by others. Shapiro also highlights the interesting and thought provoking idea of identity for those with disabilities, and as the title indicates, the problem of frequently pitying them, especially the children with disabilities (Shapiro, 1994).

While speaking with and photographing families about this project, I came across a high school freshman who took it upon herself to become her own advocate. At only fourteen, she wrote a letter to her district representative and travelled to Frankfort, Kentucky to the capitol to read her letter and march for her rights. Although I was not expecting to hear about this when I began talking to this young woman and her mother, once they told me about the experience, I immediately knew that I wanted to feature her letter and story in this paper. In her letter, she identifies the many disabilities that she has, from being legally blind to cerebral palsy and routine seizures, and articulates her dependence on the Kentucky Medicaid program to receive the medications and services that she needs every day. As she and her family have witnessed the recent events occurring at the state and federal level in terms of accessibility to healthcare and services, she decided to take a stand herself and vocalize to the men and women that represent Kentucky her own beliefs. Taking this stance and publically speaking out to government officials is not something I could have imagined doing at fourteen, and I think her decision to do so is remarkable. This young woman's letter to her representative and the representative's response letter can be read in full at the end of this paper.

Lucy pictured with her Representative, Jason Nemes, at the Kentucky State Capitol.

As I mentioned previously, parents and family members are often some of the most prominent and active among the disability activist community. In an interview with Rosemary and Gunnar Dybwad, the two speak of the founding of what was known as "National Association of Parents and Friends of Mentally Retarded" when it began in Minneapolis, Minnesota in 1950

(*Parallels In Time: A History of Developmental Disabilities*, 1987). Such a movement and organization was twenty years ahead of its time, as similar conversations were not on the forefront of the United States until around the 1970s. This couple addressed the important role of parents and families in becoming advocates for children with disabilities. At the time, medical professionals believed that the parents of these children should be a sub-organization to the medical professionals of the community, but activist Mildred Thomson argued that these parents should act and speak independently on behalf of these children (*Parallels In Time: A History of Developmental Disabilities*, 1987). Dr. Elizabeth Boggs, mother of a significantly cognitively disabled child is also noted as a significant leader of this time and the beginning of this activist movement (*Parallels In Time: A History of Developmental Disabilities*, 1987). These two speak about how these people worked tirelessly to empower parents to teach and care for and advocate for their own children in ways that they never would have known that they could without the support of the association. This foundation is still present today, as the association has grown and changed over time to meet the current needs of the community, and without its start more than fifty years ago, the entire disability rights movement as we know it would be affected. At the end of the interview, Rosemary concludes that the parents and individuals involved in the association "have simply been turned into different kinds of people." To raise a child with disabilities and become his or her most active and outspoken advocate and supporter is a challenge, particularly for those parents who have little or no previous experience with individuals with disabilities (*Parallels In Time: A History of Developmental Disabilities*, 1987). Everyday there are new parents and families who choose to sit down and read everything they can get their hands on and then turn and be prepared to fight and rally for every single thing that their child needs or may need in the future to be successful and supported.

Another example of advocacy by parents and family members is the completion and publication of the documentary “Think of Me First as a Person,” a film started in the 1960’s and published more recently in 2006, centers around a child, Dwight, with Down syndrome and takes on perspectives from the boy himself, his sister, and Dwight Core, the child’s father the filmmaker (*Think of Me First as a Person*, 2010). The film was then worked on and ultimately completed by the original filmmaker’s grandson, George Igmire. There is also supplemental footage of Dwight in 2007, a year after the documentary was finished. Although amateur in nature, the piece is honest and reflects the positives and negatives surrounding Dwight’s life and childhood and what that means for their other children and the family. As Dwight’s sister, Cindy, experienced friends and classmates asking if they kept her younger brother in a cage while he was at home, or even refusing to come to her house if he was going to be home for fear that they would “catch” what her brother had (*Think of Me First as a Person*, 2010). Her decision at a young age to stand up for Dwight and become his advocate has shaped her entire life, and Dwight presently lives with her after their mother passed (*Think of Me First as a Person*, 2010). This film highlights just one family, but their story is not unique as they represent thousands of families across the United States, who have and continue to face a number of challenges and adversities. A significant message of the film is the idea of basic respect-respecting the child with the disability as well as those surrounding and supporting that person. It is so easy to pity and have sympathy for these people and these families, but choosing to do so is placing them in a box, isolated, rather than allowing the child to demonstrate his or her own abilities.

VII. Disability Services

The purpose of the activism and resultant legislation is to provide disabled individuals equal access, equal rights, and equal opportunities. The services provided to achieve these equalities cover a wide range from major services such as education, transportation, insurance, and employment access, to smaller necessities such as braille lettering signage for public bathrooms and accessible and built-to-code wheelchair ramps. The American Disabilities Act of 1990, as highlighted earlier, reinforced and laid a platform for the equal accessibility of so many of these services for individuals with disabilities of all kinds, while also protecting the rights of millions of Americans with disabilities under the law.

One of the major services that the government seeks to adequately provide is public transportation that is accessible to all people, regardless of disability. This goal has been one of the United States government since 1970, when Congress developed a national policy, declaring it the right of individuals facing some sort of handicap to have equal rights and accessibility to public transportation, which would be reflected in the design plans of the transportation (Katzmann, 1986).

Even with the legal components and federal regulations for transportation services, many individuals with disabilities still face challenges when trying to use the services supposedly designed for them. According to the Bureau of Transportation, a higher portion of the those with disabilities, 42 percent, utilized public transportation (bus, subway, commuter train) three or more times a week compared to 28 percent of the able-bodied people who use public transportation with the same frequency (*Data Analysis | Bureau of Transportation Statistics*). This may be due to the fact that only 65 percent of disabled citizens drive a car compared to the much higher 88 percent of non-disabled citizens (*Data Analysis | Bureau of Transportation*

Statistics). Although the use of public transportation is higher for those with disabilities, user satisfaction with transport is lower, with 49% of disabled travelers experiencing problems compared to 37 percent of non-disabled travelers (*Data Analysis | Bureau of Transportation Statistics*). These data are important in highlighting the disparities in transportation services for persons with disabilities. In doing a quick Google search of disability transportation services, many websites advertising private services are available. These services can be beneficial; however, given the high cost associated with them, these services are often not a viable option.

The world of health insurance is already a difficult one to maneuver, and adding in the necessity to be covered for one or more disabilities further complicates things. Americans with disabilities qualify for government subsidized insurance under Medicaid, with coverage for services from doctor's appointments and vision and dental appointments to long-term services and hospital stays (*Medicare.gov*). While a government supported healthcare program seems simple enough, after speaking with the parents and therapists of some children with disabilities that I know, it is easy to see how complicated the process really is and how often services provides fall short of demonstrated need.

It is likely for a child with moderate to significant cerebral palsy to have many surgeries throughout his or her life, sometimes multiple in just one year. These surgeries are performed to improve mobility, skeletal alignment and flexibility. In the eyes of the general public, these surgeries may be isolated events, so any insurance that covers the costs associated with the surgeries is appropriate and sufficient. In reality, the act of performing the surgery is only the beginning of an intense rehabilitation process that can last for several weeks or months. A doctor and physical therapist may collaborate and determine that to fully reap the benefits of the surgery, an intensive therapy program of four to five sessions weekly for ten weeks is necessary.

However, when submitting this plan to insurance, they find that the child is only covered for two therapy sessions per week. So how do you move forward? Health professionals can provide the twice weekly services, which may result in decreased progress towards the goal and lead to another necessary surgery in the future, or they can provide the necessary amount of services, and have the family pay out of pocket for the coverage difference. The latter option is frequently not an option financially for families, and the child suffers as a result.

While this is a very general example of a scenario, the message rings true for families in similar situations, and the ideas behind the example can be seen in news headlines every day. In December of 2016, Texas announced the enactment of cuts of $350 million in taxpayer money allocated to pediatric therapies for children with disabilities (Lutz and Walters, 2016). Enrollment rates in Early Childhood Intervention programs are dropping at a rate of 14 percent in recent years (Lutz and Walters, 2016). This is not an isolated incident; in New York, there is currently proposed 1.1 billion-dollar budget cut for Medicaid funding for state citizens (*Developmental Disabilities Services Face the Largest Funding Cuts Ever*, 2107). In Pennsylvania, a budget proposed in January of 2017 calls for reducing social services by 20%, which includes services provided to citizens with disabilities (*PA Budget Cuts Needed Services For People With Disabilities*, 2016). These policies and budget cuts are being developed in state offices across the country and pushed through to Washington D.C. These changes may appear fiscally responsible on a budget spreadsheet, but in reality affect real people across the United States, many of whom are some of our most vulnerable citizens. Now more than ever, advocacy for persons with disabilities in the form of equal access and equitable opportunities is so vital.

VIII. Caring for a Child with Disabilities

This section is included towards the end of the paper as caring for a child with disabilities is, in a sense, a culmination of all of the previously discussed topics within the paper. To fully take care of a child with any sort of disability, parents and caregivers must interact with disability services and educational opportunities. They need to be aware of the legislation that is in place and how it has changed and continues to change. Parents and caregivers become dedicated advocates for their children as well as all children facing similar circumstances and challenges. Without adequate knowledge of any of these topics, children may not be able to reach their fullest potential. While this idea is true for a parent of any child regardless of ability level, I think that it is especially true for children with disabilities, for they are often unable to advocate for themselves.

Beyond these basic commonalities, I think what people unfamiliar with children with disabilities most fear is just how different this process looks from child to child. Throughout this project, I have spoken with different families and children with disabilities, as well as taken photographs of these children to reflect on the importance of improving upon the opportunities and rights for these children. Pictures in this section are intended to demonstrate part of what goes into being a parent to these children, as well as take the opportunity to show how strong these children are every day.

Beyond school and at home care, for many children with disabilities regular therapy is a significant part of their weekly or even daily schedule. Therapy typically falls into the three primary categories of physical therapy, occupational therapy and speech therapy. In physical therapy, patients work to improve mobility, motor function and muscle toning as well as stability, balance, and flexibility. In occupational therapy children can learn necessary tasks to increase independence such as feeding themselves, writing or other fine motor skills. Speech therapy can vary from working with children with speech impediments to working with limited verbal or non-verbal children. Children may have the opportunity to receive some of these therapies through their school program, but many travel to an outpatient clinic to receive these services, some with different sessions as many as four times a week, depending on his or her needs.

Part of caring for a child with disabilities is looking at how that affects the child's family- their parent or parents and any siblings they may have. Parents need to be cognizant of how their level of ability and subsequent involvement in their day-to-day care will affect your other children. Will a sibling take on the role of a caretaker or other parent for your other child? Will your other children feel ignored and fall to the wayside or become a shadow in the background? How will your family's financial situation be affected overall and could it limit the possibilities of your other children? These questions just scratch the surface of what I'm sure are the thousands of questions that parents think about when they are told their child will be born with a disability or when they are later diagnosed.

The questions and concerns surrounding sibling and family interactions and how they will be affected has been studied extensively. Scientists Davey, Imms, and Fossey published the article "'Our Child's Significant Disability Shapes our Lives':Experiences of Family Social Participation," in which they studied the quality of the socialization of families with a child with significant disabilities (Davey, Imms, and Fossey, 2015). The team conducted interviews with ten sets of parents of children with significant physical disabilities between the ages of ten and eighteen to gain insight about the family's ability to participate socially (Davey, Imms, and Fossey, 2015). The results of the study showed that as the complexity of the disability increased, and as the fragility and weight of the child increased, socialization of the child and his or her family decreased (Davey, Imms, and Fossey, 2015). This decrease was reflected in the type and quality of activities chosen by the parents for the family, and parents reported that these decisions were influenced largely by past experiences with the activities (Davey, Imms, and Fossey, 2015). These results indicate to clinicians how important support can be to families with a child with disabilities, particularly for those whose child is classified as "severely impaired…heavier, incontinent or fragile in health" (Davey, Imms, and Fossey, 2015).

Nancy Murphy and Paul Carbone published information on a related topic, "Promoting the Participation of Children with Disabilities in Sports, Recreation, and Physical Activities" (Murphy and Carbone, 2008). The article points out that despite roughly eighteen percent of youth and adolescents in the United States that have a disability or chronic illness, the opportunities for physical activity program involvement are few and far between (Murphy and Carbone, 2008). Of the organizations and programs that do exist for this purpose, the Special Olympics is the largest as well as the most well-known and recognized (Murphy and Carbone, 2008). Children with disabilities are often restricted from participating at the decision of the child or family due to fear, financial barriers, or societal concern, and the distance between these children and structured physical activity continues to increase with age (Murphy and Carbone, 2008). As a result, it is not surprising to learn that children with disabilities "have lower levels of cardiorespiratory fitness, lower levels of muscular endurance, and higher rates of obesity than typical children," data that is concerning to pediatricians and parents alike (Murphy and Carbone, 2008). These health risks can lead to the development of other conditions in the future, such as diabetes or heart disease, which is even more concerning for children with already one or more disabilities and illnesses. Murphy and Carbone express how increasing this participation needs to become more of a priority to involve individuals with disabilities in regular physical activity. Even for children with moderate to significant disabilities, performing some sort of regular activity will provide the opportunity to improve health outcomes while also improving opportunities for socialization in a group setting.

Of course, adding these mentioned activities to the already overfull plate of a parent of a child with disabilities is asking a lot, and maybe too much; however, I think the important idea to take away is finding a healthy balance for your child, his or her siblings, and for your family. Being a parent is a stressful job, and parenting a child with a disability is often even more stressful. As important as it is for children with disabilities to have adequate physical activity in their lives, it is just as important for a parent to have adequate physical activity. Every family's reality is different due to size, financial situations, and location, and therefore the interpretation of physical activity will look different from family to family. For some, incorporating activity may mean having your child join a Special Olympics or similar organization's team, sometimes offered through a school which removes unnecessary burden from the parent. Maybe physical activity means meeting up with another family on Saturday mornings at the park to allow everyone the chance to get out and move, or maybe it just means pulling out the Wii and investing in a Wii fit program to get some activity in while still at home. Every family is different, and caring for a child with disabilities will look different for everyone, but it is so important to continue to support programs and people who help care for these kids, and work to increase this support in any way possible.

IX. Personal Reflection

Coming to the end of this paper, after reading and gathering material and getting to know different children and their families, my biggest question is where do I go from here? Where do we, as a modern society go from here? Looking at the history of disability and the timeline of events in just the last few decades, it is apparent how much progress has been made, how many laws have been passed, how many programs have been developed for the purpose of supporting and empowering these children. And yet, speaking with families and reading material online, it is clear that there is so much more that can and should be done.

I chose this topic myself as it has always been an area of interest for me, but as I looked into all that was available on the topic, I realized that my own knowledge just barely scratched the surface. I had formed the relationships with these kids and their families and seen them in their daily routines, but lacked the background of all that these families go through to receive services for their children. I also had never looked into the unique history of disability or recognized how many people worked their entire lives to see changes enacted for their loved ones or members of their communities. Ultimately, I wanted to learn more myself while creating a resource to share with others interested in learning about the topic or increasing their ability to advocate for this persons with disabilities. Of course, there is so much more available on the this and other related topics, but having the opportunity to look into a small amount of resources has been an impactful part of my year.

I have known Sophie for several years and watched her grow up. This past summer, I spent a week as her camp counselor at an overnight camp for children with chronic illnesses and disabilities. Here, she walks on the treadmill with assistance from a gait trainer.

The education system in America is difficult to encounter for any family with school-aged children. My parents have told me stories of all that they went through trying to get me into the correct school. We moved to a new state less than two years before I was supposed to start kindergarten, and in the county we moved to, what kindergarten you send your child to strongly influences where your child will end up for high school, which affects college options. They were faced with the pressure of their first child's college opportunities before I even walked through the first day of kindergarten. The public school system requires so much time and is often about "who you know." Now add to that trying to maneuver this system for your child with physical disabilities, developmental delays, auditory and speech problems, or likely a combination of these categories. This creates an entirely new challenge for you, your family, and most importantly, your child.

Depending on the individual child, the opportunities provided within the IEP can enable a child to be very successful, but this is not always the case. I spoke with 5th grade student Olivia, who has progressive spinal muscular atrophy, about her school experiences. Although not yet in middle school, Olivia has gone to several schools to try and find the best option to meet her needs. Although physically she is confined to a wheelchair and requiring writing assistance writing due to the progressive nature of her disease, she is cognitively at the fifth-grade level, so putting her in a special education classroom would be doing her a disservice as she is just as capable of learning the material as her able-bodied peers. When she was younger, Olivia had an aide that travelled from class to class with her, and took her to the bathroom to assist her when needed. This year, although she is less physically able than she was two years ago, she is in her classroom without an aide. Whether this is due to budget cuts at the school or district level I'm not sure, but Olivia mentioned that she does wish she had an aide- she notices how her handwriting becomes less legible throughout the day and struggles because the staff member to help her in the bathroom will only come in a couple of times within the day, so instead of going to the bathroom when she needs to go, she is on a fairly strict schedule. Some parents speak online about how under their child's IEP, they transition between special education or tutoring sessions and the regular classroom setting at the school (*Public or Private? What each has to offer your special needs child*, 2010). For some, this provides a different environment throughout the day and can be stimulating, but others have found this overwhelming and confusing more than anything else (*Public or Private? What each has to offer your special needs child*, 2010).

Olivia, whose story is included above, works on a bike with her physical therapist to strengthen her lower limbs.

I have spent a considerable amount of time in outpatient clinics for pediatric therapies, from shadowing in the physical therapy gym to working the front desk to spending time with families and taking their pictures for this project. I wanted to take the opportunity to share just how important and impactful I think that these places and therapists are. I have seen children come through the front door tired and upset from a long day at school, with parents looking just as tired. These parents spend their days transferring their children in and out of wheelchairs, into the car, and doing more work in one day than many would ever think possible. Sitting in on some therapy sessions and speaking with the parents, they always seem so grateful to have the chance to take a break, even if only for forty-five minutes, and allow their child to be under the care of someone else. The child-parent-therapist relationships extend far beyond the weekly sessions. Many of these children have had the same therapist for ten years or more, and parents have spoken with me about how they consider them to be a part of the family, inviting them to birthday parties and school performances, watching them show up to the hospital after their child has had surgery, finding the time to work in extra sessions when necessary, sometimes even at the child's own home. The care that they receive from therapy is crucial to their development, and this is made so clear through these relationships and hearing these stories. The kids enjoy coming to therapy, and even when the work is hard or something that they do not want to do, they are fully supported and environment they are in is empowering.

Marshall had a stroke at age five and now spends four days a week at a variety of therapies. Here, he is pictured working on his motor skills with this instrument set.

I was particularly impacted by the information that I found in my research regarding the overlap of race and disability in the classroom, as this is nothing I had ever previously noticed or considered. It led me to wonder if any of the children I have spent time working with have ever experienced similar issues of prejudice in their own lives. Why is it that black students represent a disproportionate amount of the disabled students learning in the more restrictive and isolated classrooms? Does this stem from parent's knowledge to effectively advocate for their child? Is the fault at the hands of the school administrations or on the recommendations of the teachers in the classroom? I do not think it is fair to blame just one group or person, but rather recognize that this is a systemic problem that needs to be recognized and further addressed by all parties involved. To ignore the problem is to worsen it, and no one suffers more from this than the children in the classrooms. To advocate for children with disabilities and their rights without recognizing how interconnected the problem is with problems of race and socioeconomic status, is doing a disservice to the very people we are advocating for. This idea of ability tied to a child's race and socioeconomic status was something that I had not previously given much thought to, but in reading the literature and comparing this to families and their children's situations, it makes perfect sense. To work for these children, we must take the time to recognize all parts of the issue and fight for the betterment of all children with disabilities, not just a select group.

The information I came across about race and disability made me think of Rae, who I have known for several years. She has spoken with me several times about challenges she has faced in the classroom.

Moving forward, how do we work to effectively change the way persons with disabilities are viewed and subsequently, how people view their potential (or lack thereof) to contribute as a member of society? Disability, and the idea of "ableism", are included frequently with discrimination due to age, gender, and race. As I touched on earlier, this was a factor in my interest in writing about this topic- the history of this movement stretches more than half of a century, and yet one would struggle to find anything on the movement in American history books used in our classrooms. This sends a message of invisibility to a huge part of the people in this country, but also because of the detrimental effects the lack of inclusion has on our potential to move forward. I was fortunate enough to grow up with a parent who works with children with disabilities, so I was around children and adults with disabilities from a young age. Disability became a part of what I understood as reality for many people. And yet, many children never have this exposure as a child, and without being taught anything about people with disabilities or the history of this movement in the classroom, they grow up unsure and hesitant to interact with people with disabilities, for fear of offending or misunderstanding them.

The responsibility rests on the shoulders of every American to act with intention and empathy at all times. It is important to raise awareness and advocate for these children among the current adult population, but to make the decision to be more inclusive of the disability movement is to teach inclusivity from a young age, allowing knowledge to empower future generations to see beyond a disability when it comes to opportunities for education, employment, and overall inclusivity. We, as a society, need to do a better job of teaching children and future generations that beyond physical, developmental, cognitive and emotional disabilities is the humanity that exists in everyone. If the history of the disability movement were taught in the classroom along with the Women’s Rights Movement and Civil Rights Movement, more children could grow up with the desire to go into a field to work with those with disabilities rather than remain uncomfortable in their presence. Including this history could inspire future special education educators, future legislators fighting for individuals with disabilities, and future physical, occupational, or speech therapists.

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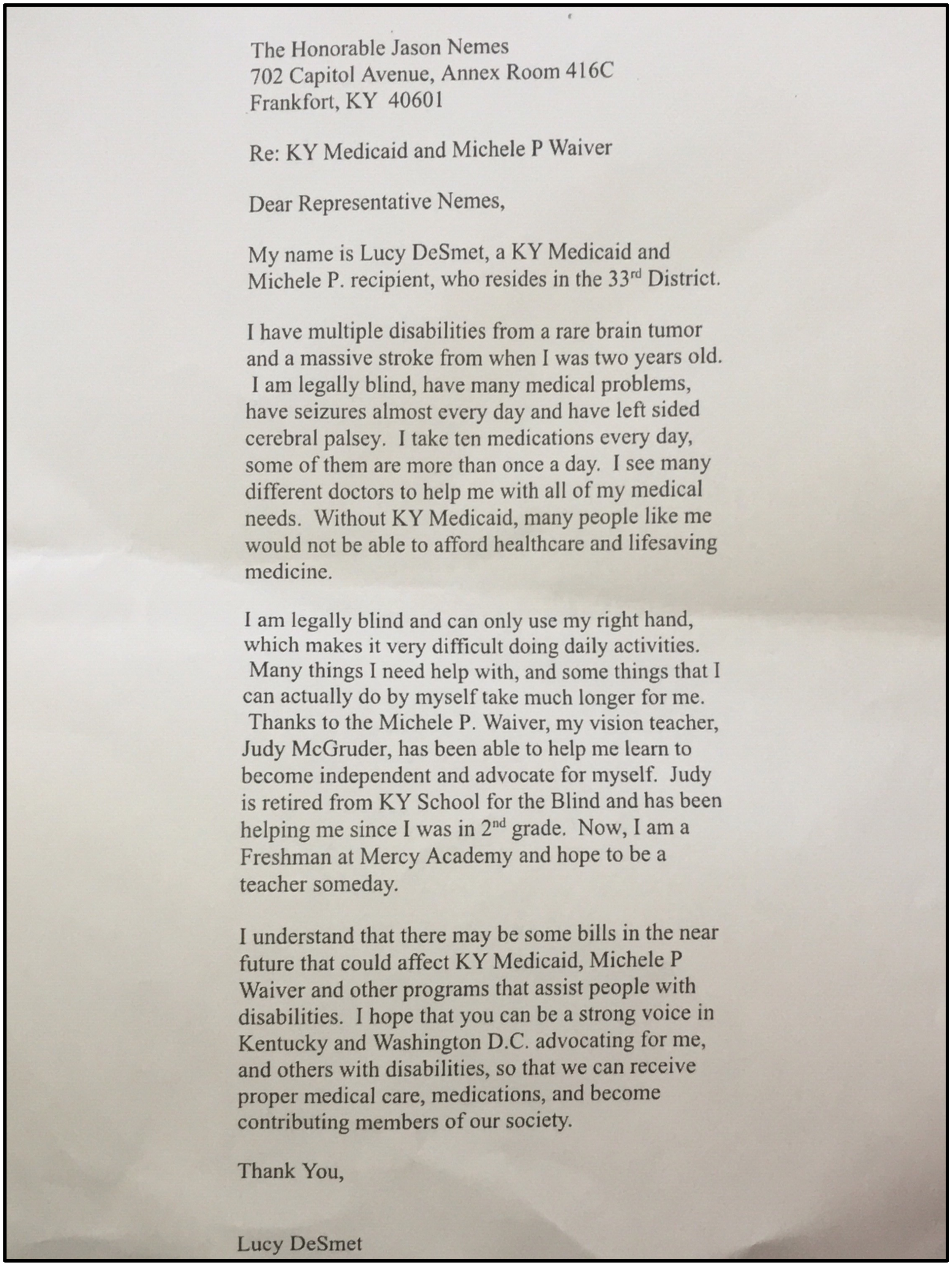
XI. Appendices

Appendix A: A letter written by high school student to her district representative, vocalizing her concern for funding cuts at the state level for Medicaid.



The Honorable Jason Nemes
702 Capitol Avenue, Annex Room 416C
Frankfort, KY 40601

Re: KY Medicaid and Michele P Waiver

Dear Representative Nemes,

My name is Lucy DeSmet, a KY Medicaid and Michele P. recipient, who resides in the 33rd District.

I have multiple disabilities from a rare brain tumor and a massive stroke from when I was two years old. I am legally blind, have many medical problems, have seizures almost every day and have left sided cerebral palsey. I take ten medications every day, some of them are more than once a day. I see many different doctors to help me with all of my medical needs. Without KY Medicaid, many people like me would not be able to afford healthcare and lifesaving medicine.

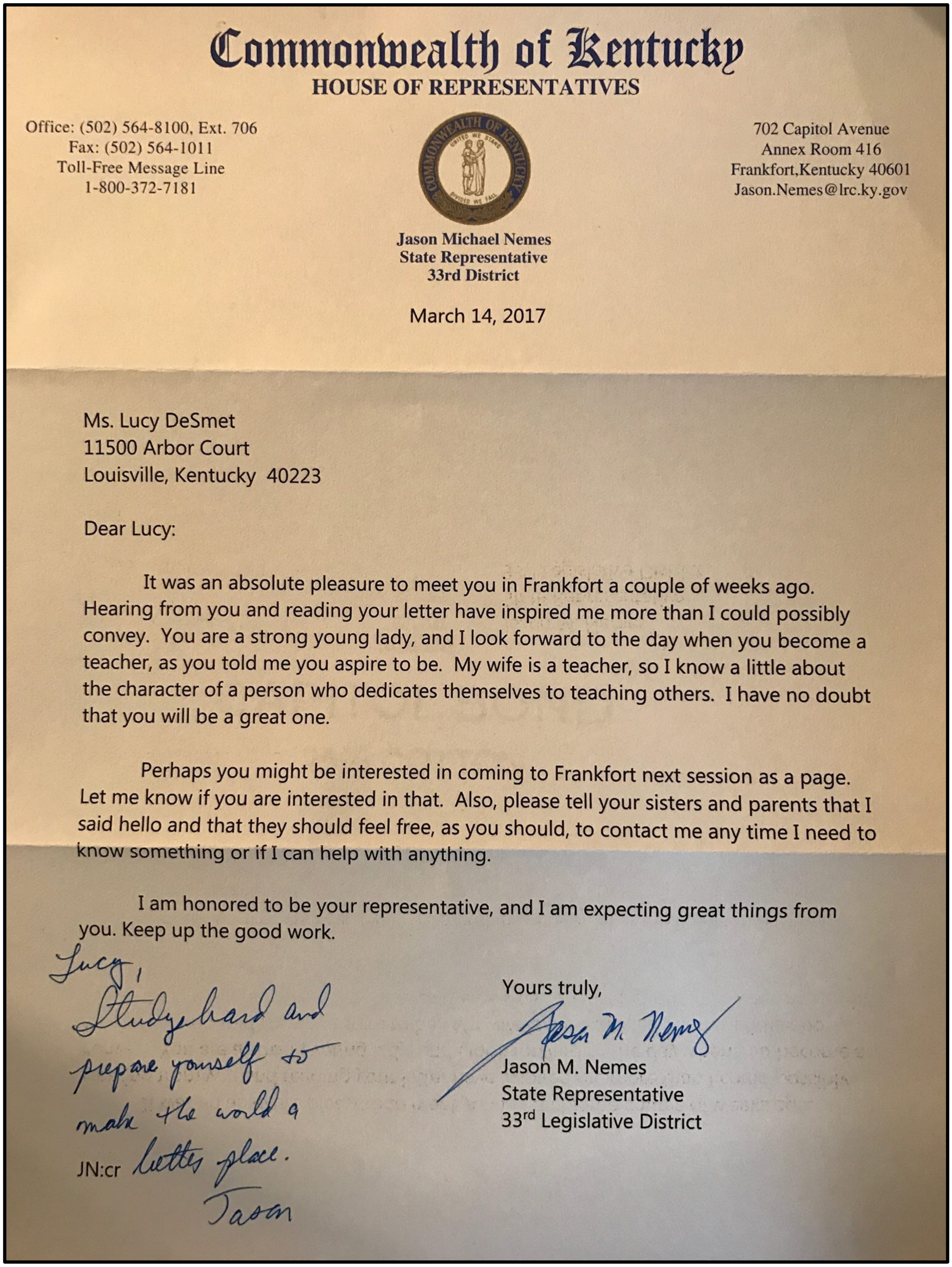
I am legally blind and can only use my right hand, which makes it very difficult doing daily activities. Many things I need help with, and some things that I can actually do by myself take much longer for me. Thanks to the Michele P. Waiver, my vision teacher, Judy McGruder, has been able to help me learn to become independent and advocate for myself. Judy is retired from KY School for the Blind and has been helping me since I was in 2nd grade. Now, I am a Freshman at Mercy Academy and hope to be a teacher someday.

I understand that there may be some bills in the near future that could affect KY Medicaid, Michele P Waiver and other programs that assist people with disabilities. I hope that you can be a strong voice in Kentucky and Washington D.C. advocating for me, and others with disabilities, so that we can receive proper medical care, medications, and become contributing members of our society.

Thank You,

Lucy DeSmet

Appendix B: The response letter from the letter above from Kentucky Representative Jason Nemes to Lucy.



Commonwealth of Kentucky
HOUSE OF REPRESENTATIVES

Office: (502) 564-8100, Ext. 706
Fax: (502) 564-1011
Toll-Free Message Line
1-800-372-7181

702 Capitol Avenue
Annex Room 416
Frankfort,Kentucky 40601
Jason.Nemes@lrc.ky.gov

Jason Michael Nemes
State Representative
33rd District

March 14, 2017

Ms. Lucy DeSmet
11500 Arbor Court
Louisville, Kentucky 40223

Dear Lucy:

It was an absolute pleasure to meet you in Frankfort a couple of weeks ago. Hearing from you and reading your letter have inspired me more than I could possibly convey. You are a strong young lady, and I look forward to the day when you become a teacher, as you told me you aspire to be. My wife is a teacher, so I know a little about the character of a person who dedicates themselves to teaching others. I have no doubt that you will be a great one.

Perhaps you might be interested in coming to Frankfort next session as a page. Let me know if you are interested in that. Also, please tell your sisters and parents that I said hello and that they should feel free, as you should, to contact me any time I need to know something or if I can help with anything.

I am honored to be your representative, and I am expecting great things from you. Keep up the good work.

Yours truly,

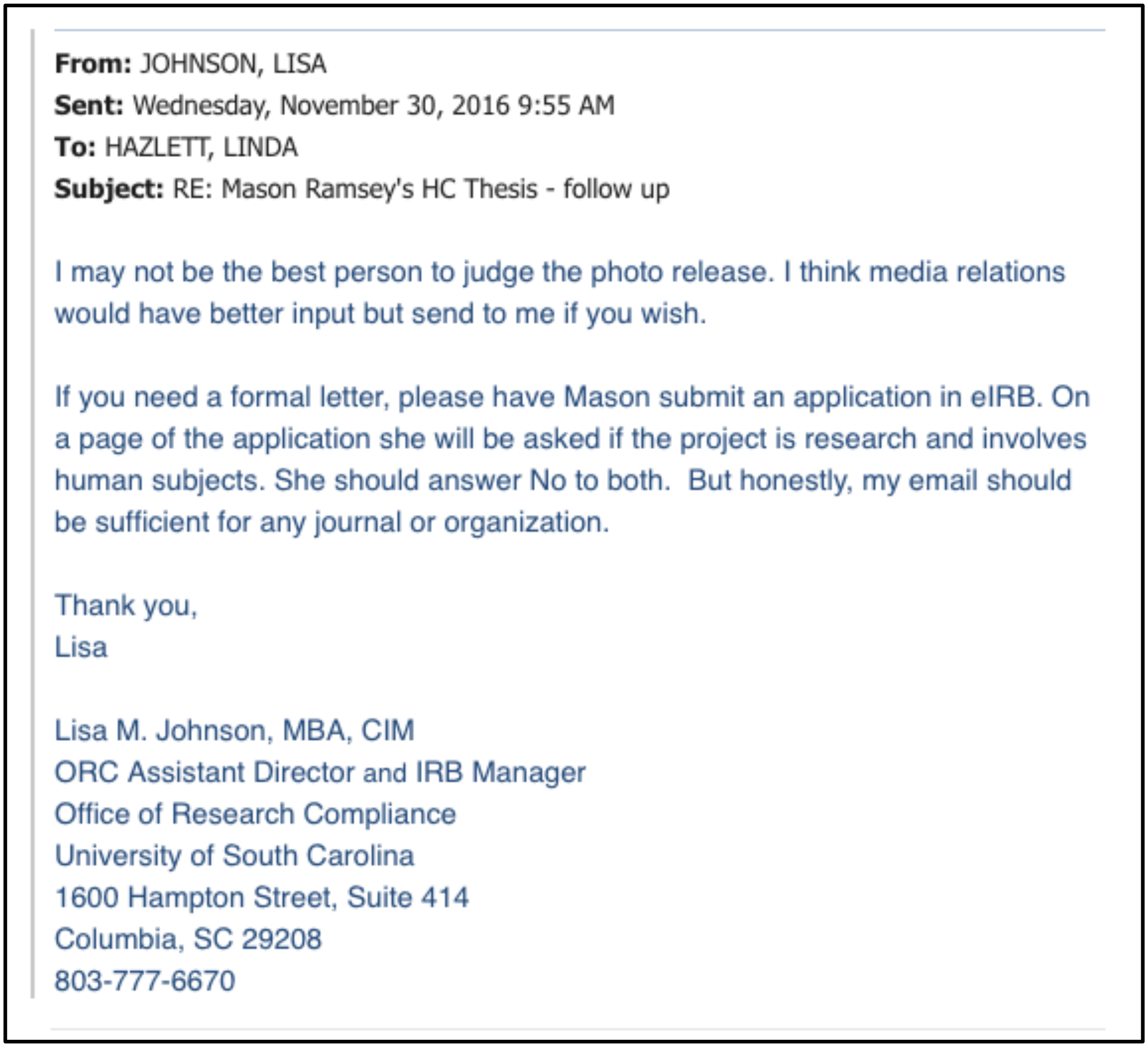
Jason M. Nemes

Jason M. Nemes
State Representative
33rd Legislative District

Lucy,
Study hard and
prepare yourself to
make the world a
better place.
Jason

JN:cr

Appendix C: An e-mail from IRB Manager Lisa Johnson, offering permission to use photographs for the Thesis Project.



From: JOHNSON, LISA
Sent: Wednesday, November 30, 2016 9:55 AM
To: HAZLETT, LINDA
Subject: RE: Mason Ramsey's HC Thesis - follow up

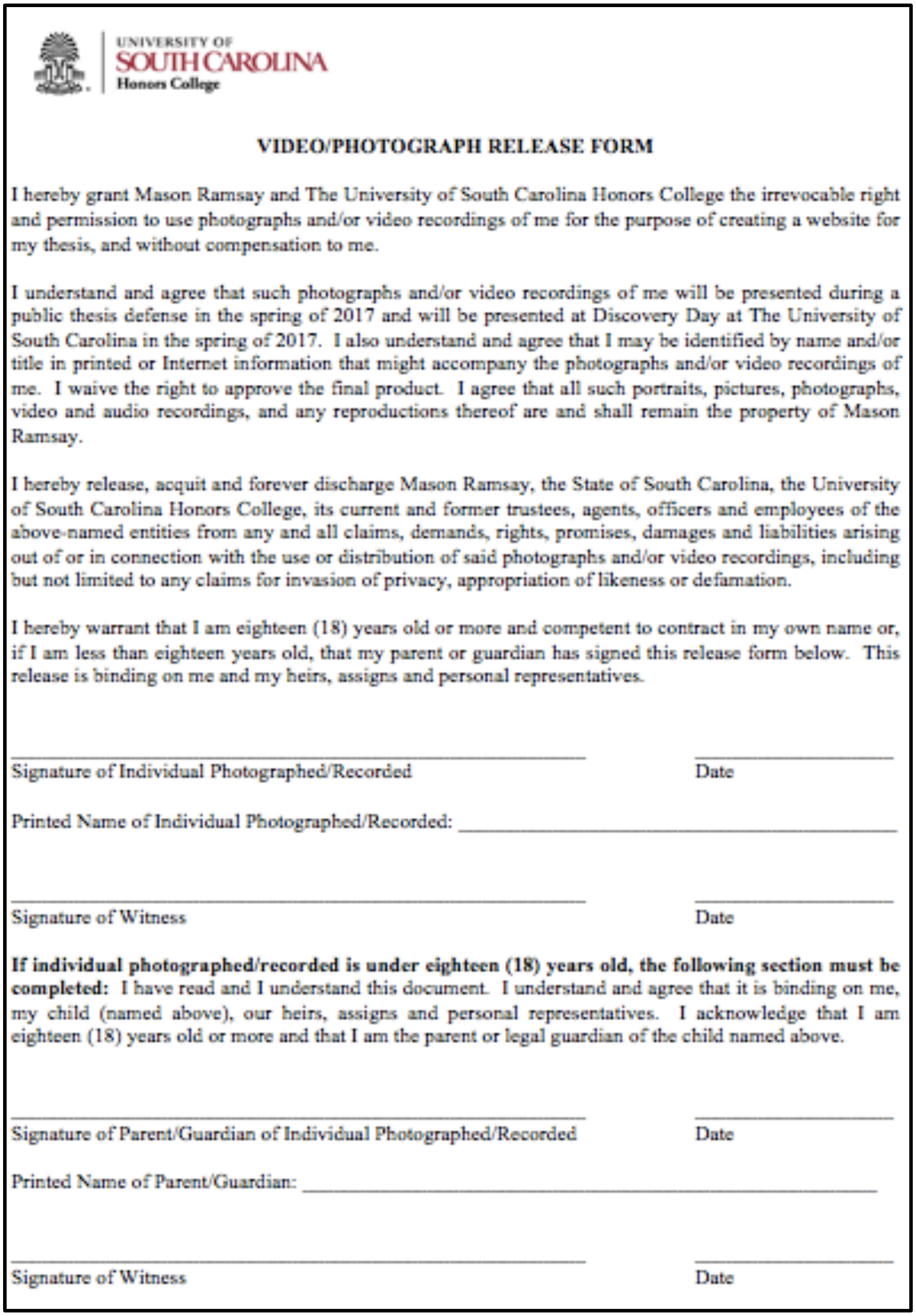
I may not be the best person to judge the photo release. I think media relations would have better input but send to me if you wish.

If you need a formal letter, please have Mason submit an application in eIRB. On a page of the application she will be asked if the project is research and involves human subjects. She should answer No to both. But honestly, my email should be sufficient for any journal or organization.

Thank you,
Lisa

Lisa M. Johnson, MBA, CIM
ORC Assistant Director and IRB Manager
Office of Research Compliance
University of South Carolina
1600 Hampton Street, Suite 414
Columbia, SC 29208
803-777-6670

Appendix D: The photo release form that was signed by all photographed participants or their parents/guardians.



UNIVERSITY OF
SOUTH CAROLINA
Honors College

VIDEO/PHOTOGRAPH RELEASE FORM

I hereby grant Mason Ramsay and The University of South Carolina Honors College the irrevocable right and permission to use photographs and/or video recordings of me for the purpose of creating a website for my thesis, and without compensation to me.

I understand and agree that such photographs and/or video recordings of me will be presented during a public thesis defense in the spring of 2017 and will be presented at Discovery Day at The University of South Carolina in the spring of 2017. I also understand and agree that I may be identified by name and/or title in printed or Internet information that might accompany the photographs and/or video recordings of me. I waive the right to approve the final product. I agree that all such portraits, pictures, photographs, video and audio recordings, and any reproductions thereof are and shall remain the property of Mason Ramsay.

I hereby release, acquit and forever discharge Mason Ramsay, the State of South Carolina, the University of South Carolina Honors College, its current and former trustees, agents, officers and employees of the above-named entities from any and all claims, demands, rights, promises, damages and liabilities arising out of or in connection with the use or distribution of said photographs and/or video recordings, including but not limited to any claims for invasion of privacy, appropriation of likeness or defamation.

I hereby warrant that I am eighteen (18) years old or more and competent to contract in my own name or, if I am less than eighteen years old, that my parent or guardian has signed this release form below. This release is binding on me and my heirs, assigns and personal representatives.

Signature of Individual Photographed/Recorded — Date

Printed Name of Individual Photographed/Recorded: ____________________

Signature of Witness — Date

If individual photographed/recorded is under eighteen (18) years old, the following section must be completed: I have read and I understand this document. I understand and agree that it is binding on me, my child (named above), our heirs, assigns and personal representatives. I acknowledge that I am eighteen (18) years old or more and that I am the parent or legal guardian of the child named above.

Signature of Parent/Guardian of Individual Photographed/Recorded — Date

Printed Name of Parent/Guardian: ____________________

Signature of Witness — Date