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HEALTH CARE BASED SERVICES IN THE UNITED STATES: AN ANALYSIS OF THREE ALTERNATIVE REFORMS TO IMPROVE SERVICES AND DECREASE WAITING LISTS

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B.A., Southern Illinois University, 2012

A Research Paper
Submitted in Partial Fulfillment of the Requirement for the
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TABLE OF CONTENTS

LIST OF FIGURES

CHAPTER 1

INTRODUCTION

In the United States communities are growing and becoming increasingly more diverse. The land of opportunity has sparked interest in people all over the globe to seek lives in the United States. According to the 2010 United States Census, the population of the United States is on the rise, and so are the numbers of diverse cultures within the country. In 2009, 13% of the county's population consisted of foreign-born peoples, and approximately 680,000 legal immigrants are naturalized annually. With this large influx of people entering the community, it's only natural and necessary that these communities become more culturally competent. According to Northouse, (2010), cultural competency is a set of congruent behaviors, attitudes, and policies that come together in a system, agency, or among professionals, enabling effective work in cross-cultural situations. Cultural competency is necessary so that everyone can live safely and comfortably in a cohesive community. However, there are groups that exist in every population worldwide which typically is often overlooked in the discussion of diversity. This is the population of individuals with developmental disabilities. According to Substance Abuse and Mental Health Information Center of St. Louis Missouri (SAMHI), one out of every thirty-five Americans may suffer from a form of developmental disability, which is approximately 3% of the American population. However, statistics show that only about 240,000 individuals are in public and private residential facilities, and 800,000 are in regular and special education classrooms.

This study seeks to observe the known causes and factors that can lead to developmental disabilities. This is important because it will help us understand the scope of the problem being faced within our society. The study will also observe the private and public services that are

available to these individuals and their families. The primary focus of this study is to entertain

how public policy and a promoted educational campaign can aid in reducing state waiting lists

for individuals with a intellectual and developmental disability, and aid in better quality of

services received. These ideas could also aid in recruiting and educating advocates for

individuals with developmental and intellectual disabilities, and overall improve services and

availability of services.

The analysis will examine popular marketing trends and social media outlets to see the

effects they have on reaching the maximum number of people possible. Through these efforts of

raising awareness, we can make an estimated projection of how it could impact the population of

developmentally disabled individuals and their families. The paper proceeds as follows. First,

the scope and severity of the problem is documented and some of the most important reasons

why so many Americans with developmental disabilities are identified.   After analyzing the

problem, the methodology for evaluating current popular marketing strategies through social

media for improving treatment of Americans with developmental disabilities is explained and the

criteria for an effective policy presented. The evaluation of the current contemporary approach,

an enhanced approach on increased focus on children at risk, and a proactive approach,

observing current marketing trends, are followed by the recommendations and conclusion.

CHAPTER 2

BACKGROUND AND PROBLEM ANALYSIS

According to the Developmental Disability Resource Center, (2014), "Developmental Disability means a disability that is manifested before the person reaches twenty-two (22) years of age, which constitutes a substantial disability to the affected individual, and is attributable to mental retardation or related conditions which include cerebral palsy, epilepsy, autism or other neurological conditions when such conditions result in impairment of general intellectual functioning or adaptive behavior similar to that of a person with mental retardation." Often times, when individuals with developmental disabilities are referred to, the general public assumes these individuals are Intellectually Disabled (ID), (mentally retarded). However, as the definition shows, intellectual disabilities are just a sub category in the overall problem. Conditions such as epilepsy, autism, cerebral palsy, and other neurological conditions are also considered under the umbrella of the term 'developmental disabilities'. This is because of the way these conditions can delay the developmental process physically, as well as mentally. In many cases, individuals who have a developmental disability also have a relatively high Intelligence Quotient (IQ). Although these individuals may be able to perform many, if not most tasks independently, their developmental disability could still require them to need assistance in some areas.

Although intellectual disabilities are only a subcategory of developmental disabilities, many are afflicted. As opposed to other developmental disabilities, Intellectually Disabled persons are at a greater chance of having an inability to care for one's self or make important decisions independently. To further illustrate this we must understand what constitutes being intellectually disabled, and what are its known causes.

Intellectual disability is below-average intelligence or mental ability and lack of skills necessary for living day-to-day life, WebMD, (2014). Individuals with Intellectual Disability have an Intelligence Quotient ranging from 70-75. The Average IQ of an individual without an Intellectual Disability is around 100. Individuals with an intellectual disability are limited in two areas, intellectual functioning and adaptive behaviors. Individuals with intellectual functioning limitations have difficulty learning, reasoning, making decisions and solving problems. Adaptive behavior limitations rob these individuals of the skills necessary for day to day living. These are skills such as effective communication, interacting with others, and the ability to take care of one's self. Intellectual disabilities can range on a spectrum from mild to profound. Individuals with a mild form of intellectual disability are very common. These individuals are able to perform many tasks on their own and under the supervision of others. Profound disabilities are individuals who are in need of constant attention and care.

According to the Centers for Disease Control and Prevention, (2015), There are many factors that can be related to the cause of an intellectual disability including individuals genetically pre-disposed to intellectual disabilities, such as Down Syndrome and Fragile X Syndrome. Problems during pregnancy and birth can also be factors leading towards ID. Drug and substance abuse are also major factors of birth defects. Issues during the birth cause many of these problems, such as oxygen deprivation and premature birth. According to the Physicians Committee for Responsible Medicine, approximately 120,000 babies are born with birth defects each year. Also, approximately 3% of all children born in the United States have a major malformation at birth. Finally, injuries and illness can be a cause of intellectual disabilities, such as whooping cough, measles, and serious head injuries.

Historically, not enough has been done to address some of these issues facing our society and to help improve the wellbeing of individuals with developmental disabilities and their families. The public's lack of knowledge has contributed to insufficient help and services being made available. It also has facilitated discrimination towards individuals with developmental disabilities. According to the United States' Congress (in PL.101-136: The Americans with Disabilities Act of 1990),"Historically, society has tended to isolate and segregate individuals with disabilities, and, despite some improvements, such forms of discrimination against individuals with disabilities continue to be a serious and pervasive social problem." Over the past one hundred years, legislation, policies, and services for the developmentally disabled have taken a roller-coaster course to arriving where we are today. In the late Ninetieth Century and early Twentieth Century centralized locations were developed to institutionalize Individuals with Developmental Disabilities, West Virginia Developmental Disabilities Council (WVDDC), (2014). The ideas of these institutions were originally conceived to help protect individuals with developmental disabilities from the general public. However, over the first half of the Twentieth Century, these institutions took a turn from their original position of keeping these individuals safe, to institutions of dehumanization and stigmatization. Legislation was passed forbidding individuals with developmental disabilities from participating in marriage. These institutions also began sterilizing these individuals so that they would not be able to give birth under the assumption that this would decrease the amount of children born with developmental disabilities. Legislation also allowed for institutions to take no part in the rehabilitation of these individuals, WVDDC, (2014).

Beginning in the 1950's some things began to improve as steps were taken to change services to assist individuals with developmental disabilities. In 1953 the National Association

for Retarded Children (NARC) was formed. Today the organization still exists under the name, The Arc of the United States (Arc), Arc.org, (2014). This organization was established in basements of churches and vacant buildings by parents and concerned citizens, hoping to improve the situation of individuals with DD. Through the efforts of establishments such as these, the concern for individuals with DD began to spread across the world. By the 1960's Parents Organizations had been developed in sixty-plus countries, WVDDC, (2014).

It wasn't until the 1960's that the federal government took an interest in the problem. New legislation established rights and provided services to individuals with developmental disabilities. President John F. Kennedy was the pioneer who helped propel this change of rights and services for the Developmentally Disabled. According to the John F. Kennedy Library, (2017), "On October 11, 1961, President Kennedy announced his intention to appoint "a panel of outstanding scientists, doctors, and others to prescribe a plan of action in the field of mental retardation." He added, "The central problems of cause and prevention remain unsolved, and I believe that we as a country, in association with scientists all over the world, should make a comprehensive attack." This panel focused on awareness that Individuals with DD are facing separation and exclusion from many public and private institution activities, such education within school systems. The panel also took interest in the public institutions that had been operating to keep these individuals away from the general public. It was brought to their attention that these institutions were grossly underfunded and rank with systematic abuse and neglect. This sparked the ideas of civil rights for individuals with DD, and also formed the concept of "Normalization" which means making available to Individuals with Developmental Disabilities.

Throughout the rest of the Twentieth Century legislation became more and more

effective in addressing the problems and issues faced by the population of special needs individuals. Throughout the 1970's, leaps and bounds were established through legislation. The 1975 amendments set a standard for the rights of individuals with DD, and their ability to receive appropriate treatment and services. These amendments stated that the government would not fund any facility that did not meet the standard for providing nutritious diet, medical and dental services, prohibition of physical restraints, visiting rights for relatives, and compliance with fire and safety, Administration for Community Living (ACL), (2017). The U.S Government also began establishing services available for Individuals with DD. In 1978, services such as case management services, child developmental services, alternative community living arrangement services, and non-vocational social-developmental services were established. Throughout the 1980's and 1990's, services continued to develop in aiding individuals with DD. These services and amendments began focusing not only on the civil right and protection of these individuals, but also on programs established to help educate and rehabilitate these individuals so that they may be able to live a more independent lifestyle. These steps towards improving services available for individuals with DD proved to be extremely necessary, especially because of the rising numbers of Individuals with Developmental Disabilities. The 1983 New York Times stated that the number of babies born with physical and mental defects had doubled in the twenty-five years prior to 1983. These problems have not been getting better since the 1983 article. According to SAMHI, (2014), approximately every 5 minutes a child is born with mental retardation, and as stated previously approximately 120,000 children are born with birth defects each year in the United States. There is no known cure for individuals with developmental disabilities and there doesn't appear to be one developed in the near future. Every year there are going to be more individuals in society with a developmental disability. However, in the United

States today individuals are not facing the same hardship they were fifty years ago.

Lack of resources seriously constrains the level of services available for individuals with developmental and intellectual disabilities. The services available for individuals with developmental disabilities are life-changing developments established to aid the individual with safe living arrangements, healthcare provisions, work opportunities, and habilitation programs. These services are made available through Medicaid funding. According to United Cerebral Palsy (2014), "Medicaid affects so many—children and adults with disabilities, the elderly and folks living in poverty. It is the critical safety net that provides financial and health care security and community support to Americans, including those with ID/DD, so their desired freedom, quality of life and community participation can be fully realized." Through Medicaid funding, which specific services are made available for individuals with developmental disabilities and how can these services help better their lives?

There are several different services available to individuals with DD that can be specifically tailored to specific disabilities. According to the Illinois Department of Human Services (DHS), (2014), the services available for qualified individuals with developmental disabilities include; Residential Living Arrangements, In-Home Supports, Day Services, Support Service Teams, and Early Intervention Services. Residential Living Arrangements consists of homes that provide services by having qualified staff available to the residents twenty-four hours per day. Although individuals living outside of a residential living arrangement also qualify for these services, residential living arrangements will help coordinate a number of additional services available such as, adaptive equipment, speech and language therapy, occupational therapy, physical therapy, behavior therapy, and respite care. Residential living arrangements will also often work with Support Services Teams to provide on-site technical assistance and

training for persons with a developmental disability. These teams are composed of Nurses,

Qualified Intellectual Disability Professionals, Board Certified Behavior Analysts, and

Psychologists. The professionals on these teams respond to individuals with behavioral or

medical challenges resulting in their inability to live and thrive in the community. In-Home

Supports are services available to assist individuals to live more independently in their own

home. Day Services are workshops, skill training, and job training services established to help

individuals with developmental disabilities succeed in the workplace. Day Services also provide

the opportunity for these individuals to perform jobs and tasks within their skill range for

compensation. Finally, Early Intervention services are available to children between the ages of

0-3 years old with disabilities. These services help children with disabilities learn and grow so

they can mature as normal as possible.

   As previously mentioned, the major problems being faced by individuals with

developmental disabilities are the lack of services available to them. The Cornell University

Employment and Disabilities Institute (EDI), (2014), developed an online resource for disability

statistics using the U.S Census Bureau 2012 American Community Survey. These statistics state

that of all non-institutionalized people of all gender, race, age, and educational level,

approximately 12.1% of individuals reported having a disability. This means that about

37,627,800 individuals out of a base population of 309,936,400 (with a margin of error of ±0.05)

are reporting to have a disability. For the purposes of the survey, the definition of disability was

based on questions surrounding six areas; Hearing Disability, Visual Disability, Cognitive

Disability, Ambulatory Disability, Self Care Disability, and Independent Living Disability, EDI,

(2014).

   These numbers are extremely important when considering the scope of the problem being

faced by individuals with developmental disabilities, especially when they are compared to statistics concerning services that are available, and services that are being received. Data collected from the National Survey of Day and Employment Programs state, "in fiscal year 2009, approximately 560,979 individuals received day or employment support from the state IDD agency"(Institute for Community Inclusion (ICI), 2011). This example is just an estimated figure to illustrate the significance of the problem currently being faced. However, the figure from fiscal year 2009 does indicate an approximate 100,000-person increase since fiscal year 1999. One could say that 100,000 more people in ten years is a significant increase, and although it is a good thing that it has increased, there are still a vast majority of individuals not receiving services. Also, according to the ICI (2011) data, the number of people being served on the state level is far from being consistent among the differing states, which is a continuous trend. The difference in the numbers between states can be very dramatic as well.

The fiscal year 2009 data reports that one of the states with the most individuals being served is New York, serving 66,469 individuals with a developmental disability. Adversely, the worst performing state in 2009 was Arkansas, serving 1,174 individuals with a developmental disability. Although New York has a much larger population and more access to financial resources, the fact that Arkansas had such a drastically low number of people served is a severe problem. Many other rural states displayed very similar numbers to those of Arkansas. However, Illinois, which also contains one of the largest cities in the country, does not compare to New York, with a population being served of 28,896. A compelling argument can be made that many people are simply unaware of the fact that there are services available to them. This argument could especially be true in rural states such as Arkansas, and could even be true for states such as Illinois and New York. However, the bigger problem is the fact that there are not enough

services and providers across the entire country. In states all over the country there are enormous waiting lists of individuals hoping to receive services. The following charts were composed and contain data from the United Cerebral Palsy's 2014 Case for Inclusion.
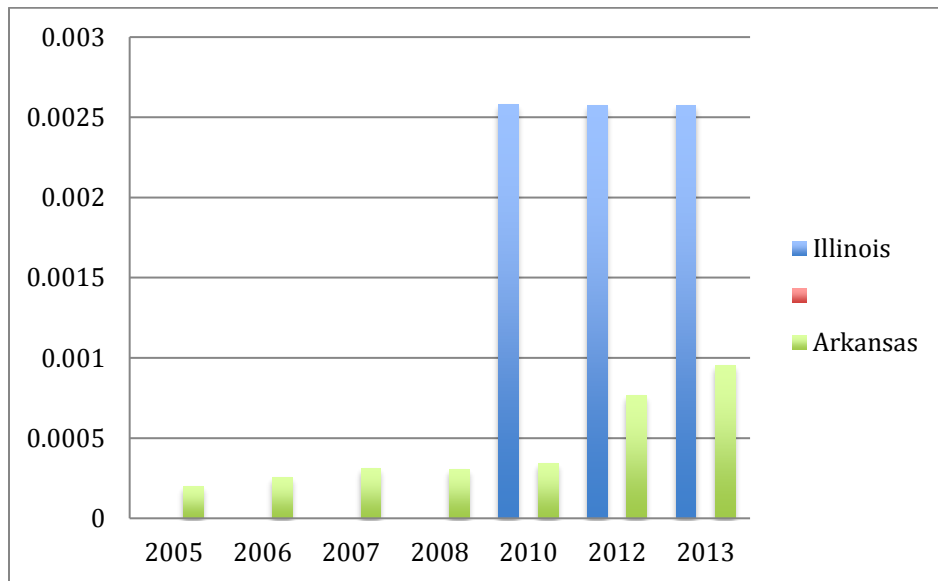

Figure 1. Percentage of Individuals on HCBS Waiting Lists

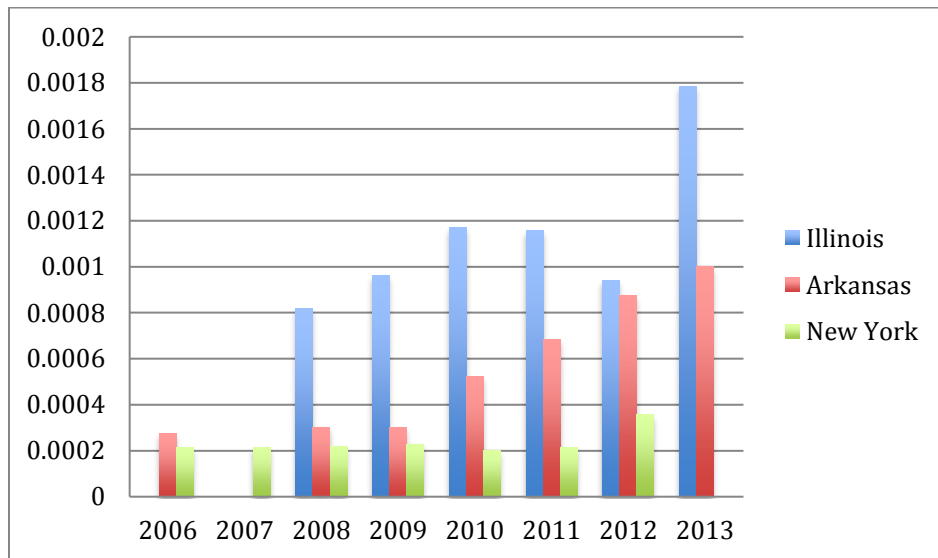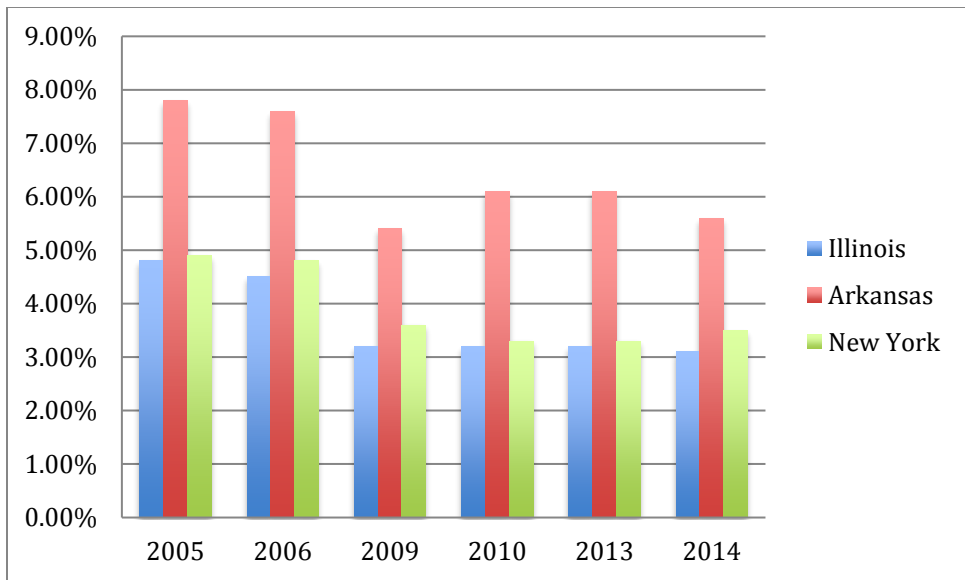Figure 2. Percentage of Individuals on Residential Waiting lists
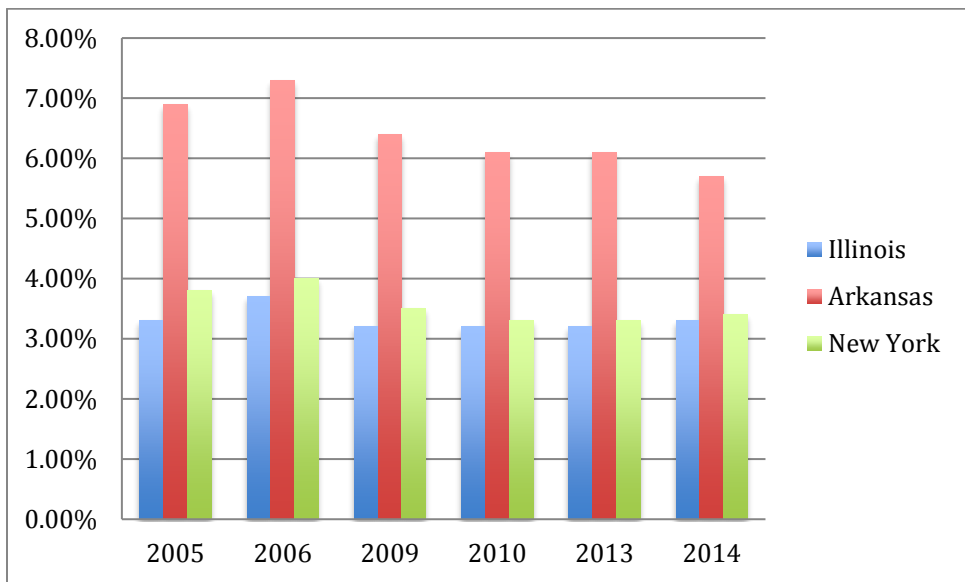
Figure 3. Children With ID/DD

Figure 4. Adults with ID/DD

These charts illustrate the state trends of data available for individuals on waiting lists for Home and Community Based Services in Illinois and Arkansas, (no available data from New York for HCBS waiting list), and also for individuals on residential waiting lists for Illinois,

Arkansas, and New York. When comparing the numbers of individuals being served and individuals on waiting lists, the problem becomes clearly illustrated. The 2009 data from the ICI reported that Illinois was serving 28,896 people with disabilities, but the case for inclusion data shows that 33,114 individuals were on HCBS waiting lists, and 15,042 individuals were on residential waiting lists in 2010. Even Arkansas, which shows a relatively small number of individuals on waiting list compared to Illinois, still has numbers that equal the numbers of individuals being served. The division between top performing states and worst performing states are vast, however, their determinants are not as clear as many would think. The characteristics of top performing states, as far as actively working to better the services available to the developmentally disabled, are not based on a specific variable. They are however, very diverse in their character. According to UCP, (2014), top performing states include characteristics of being both large and small states, rich and poorer states, high and low tax burden states, and states that have high and low spending per person. Although there are states such as New York, Arizona, and Washington that are leading the way in top performance, every state needs growth to cover the demand from individuals with developmental disabilities in need of services. Some states need drastic growth to reach the needs to support those on waiting lists.

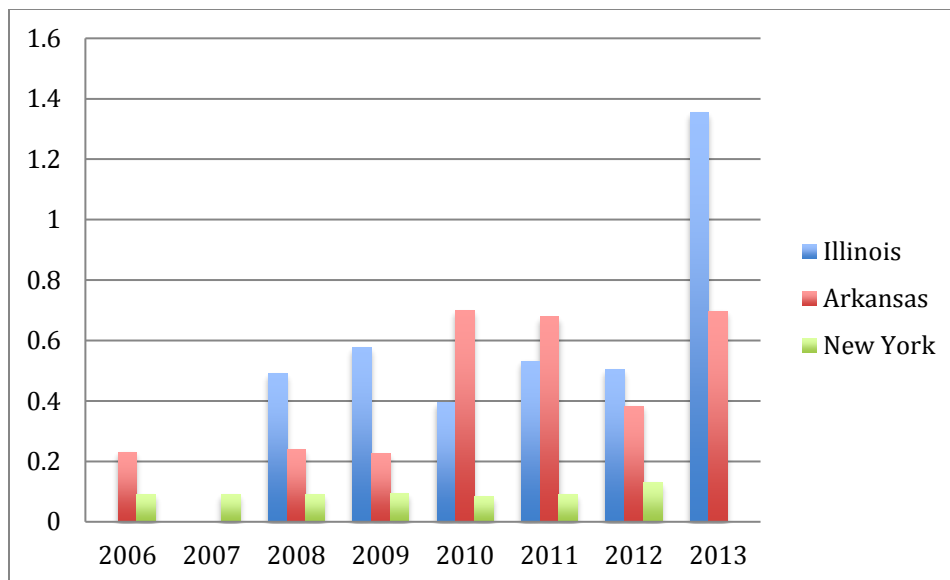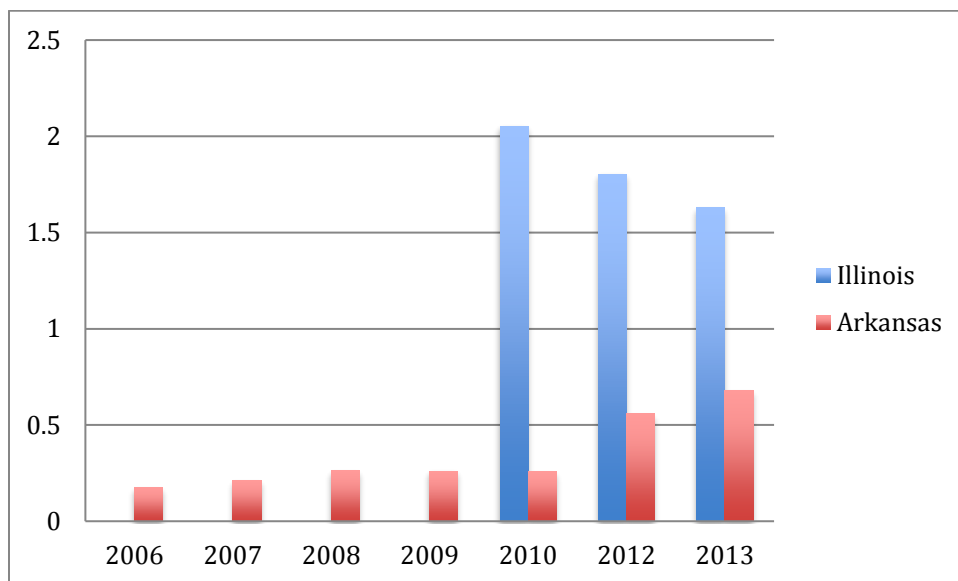Figure 5. Percentage growth in residential services to meet waiting list

Figure 6. Percentage growth in HCBS services to meet waiting list

The trends in Figure 5 and Figure 6 show the percentage amount that each state needs to grow in order to meet the waiting lists for HCBS and residential services, according to UCP, (2014). After reviewing the data on how many individuals with disabilities were on waiting lists

in these states, it is not surprising to see the percentage of growth these states need to incur. The UCP data shows that for the year 2010, Illinois needed to incur a 205% growth to meet the waiting list for HCBS services, and still a 180% growth in 2012. The trend for growth in HCBS services is not quite as significant for Arkansas, although they still show a needed 55.8% growth to occur. The national trend for the entire United States shows a needed 46.4% growth to meet the overall national HCBS waiting list. Many states vary just as the three listed above, and Illinois is not the only state with outrageous needs of growth. However, for the sake of brevity, not all states should be analyzed in this research

The National Core Indicator (NCI) collects annual data based on surveys distributed to developmental and intellectually disabled service recipients in states across the country. Many sources, such as the United Cerebral Palsy Case for Inclusion, use this data to develop their own research. For the purposes of this study, the data will be used to look even closer into how services, or lack thereof, affect individuals' lives. Primarily, the NCI surveyed three different groups to analyze their data: Adult Family Survey (AFS), Child Family Survey (CFS), and Family/Guardian Survey. The following tables are collections of data from the National Core Indicator Annual Summary Report for 2011-2012.
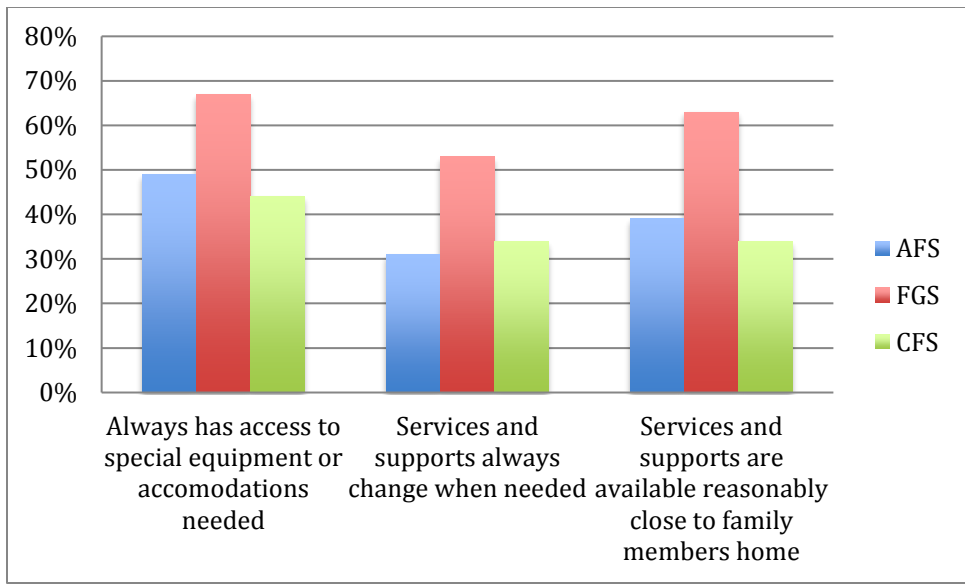
Figure 7. Access to services and supports
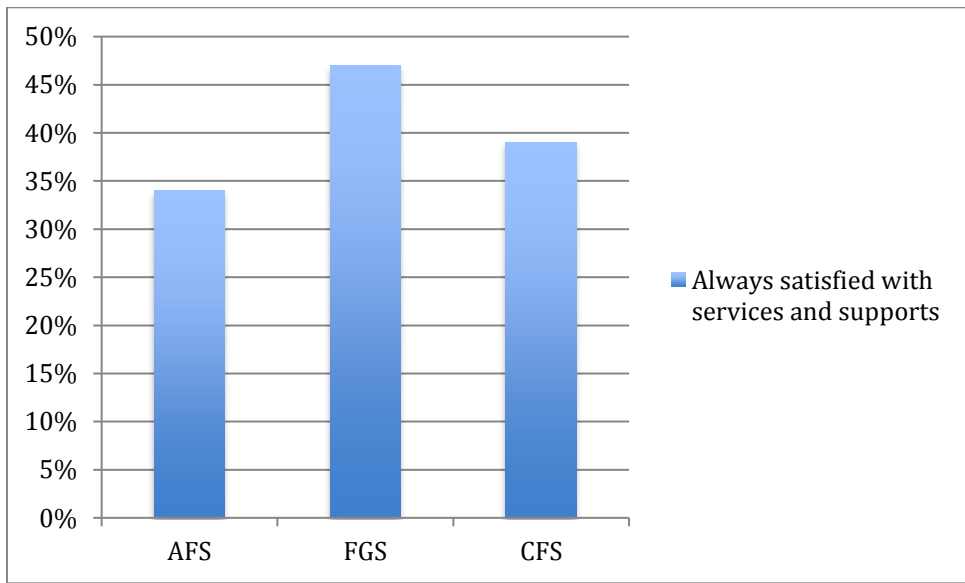
Figure 8. Always Satisfied With Services and Supports

Figure 7 and Figure 8 indicate how service recipients view the quality of the services they are receiving. The Figure 7 displays factors of high importance to service recipients, such as access to special needs equipment, flexible services, and local services. The Family and Guardian Survey reports feedback that is slightly above Adult Family Surveys and Child Family

Surveys, which reported: below 50% felt that these areas were adequate. Figure 8 reports that in all three surveys, less than half of the respondents felt that they were satisfied with services and support. This data is important to the study because it showcases that not only are the amount of resources available drastically lacking, but also the quality of services that individuals are already receiving.

Finally, unemployment complicates treatment of individuals with developmental disabilities. Unemployment is a problem that affects the entire nation, whether individuals have a developmental disability or not. Finding and working a job when a person is able bodied is a task all in its own. However, trying to find a job, work, and make any sort of income when you are challenged with a developmental disability can prove to be nearly impossible. According to the United Cerebral Palsy 2014 Case for Inclusion, "88 percent of working age adults with developmental disabilities are unemployed." Participating in employment not only allows the individual to earn an income, but it also supports self-worth and gives access to socialization outside of the family or a residential home. These factors allow for the individual to grow and live a more typical, independent lifestyle. Besides these factors, having a large population of unemployed individuals is bad for the overall economy because of the lack of money in circulation. The UCP states that increased employment of individuals with developmental disabilities is advantageous for the taxpayer. "Every $1 spent on supported employment services yields a return of $1.46, based on sales and income taxes alone generated by the individual working. Simply put, supported employment is good fiscal policy, resulting in a 46 percent return on investment"(UCP, 2014).

CHAPTER 3

AN ANALYSIS OF THREE APPROACHES TO IMPROVING DISABILITY SERVICE ACCESS

To assess the current contemporary approach, an enhanced approach on increased focus on children at risk, and a proactive approach, observing current marketing trends, data was collected quantitatively and qualitatively from scholarly articles, government databases, and private research groups. When collecting the data necessary for analysis, the research focused on the information specifically relevant to individuals with a developmental disability including the type of disability, and services available for individuals with a developmental disability. Data was also collected regarding different forms of marketing and educational campaigns including their reach and effectiveness. Once the data was collected, it was analyzed to determine the extent to which educational campaigns affect utilization of services by individuals with a developmental disability. This assesses the relative impact of three options according to cost and effectiveness. The first option will be observing the current process in which individuals with a developmental disability go through to receive services, as well as a look at how the current budget allocates funds to federal programs. The second option will observe a more advanced process of identifying individuals with a developmental disability at a younger age through an increased screening process within the educational system. The third option will then review how an educational campaign, primarily based through advertising and social media, could raise awareness about developmental disabilities and the services available for these individuals. The cost of these options will then be compared to the current policy to see whether their effectiveness would be worth their implementation.

So what needs to be done to minimize the number of individuals on waiting lists nationwide? Many states throughout the country are working hard to become better providers to those with developmental disabilities. However, many states are still lacking greatly. To promote a more successful provision of services amongst all states, it would be necessary to view the top performing states and try to apply the same practices and ideologies across the entire country. However, as with changing state policies, a great deal of knowledge is required amongst all tiers of the population and a strong political backing must be in place. Spreading knowledge of the issues facing individuals with developmental disabilities is the most important step in acting towards minimizing these issues nationwide.

There are important elements that must be addressed in order to improve the situation of many states, especially within the focus of minimizing state waiting lists. This research will observe different platforms to aid in shedding light on the issues at hand and bring change. In addition, it is necessary to identify the factors that must be implemented through these platforms to strengthen a serious change. The United Cerebral Palsy 2015 Case for Inclusion outlines the top three strategies needed to put a dent in our country's waiting lists for services. The study illustrates that the number one factor that must be addressed at the state level is the amount of transparency of information involved within the state's waiting list. Through cross comparing each state's waiting list and the amount of attention and detail each state puts towards their waiting list, the UCP has been able to identify trends in states that are improving their waiting lists and those states which remain stagnant or decreased. States with a higher degree of transparency are improving the status of their waiting lists. Also, states that kept larger amounts of information and updated information on the status of their waiting list were improving the status of their waiting list. According to the United Cerebral Palsy 2015 Case for Inclusion, the

items that should be addressed by each state are: The purpose of the waiting list (Including individuals rights); Process, ranking criteria and management of waiting list; Basic demographic information – age, sex, racial and ethnic background by region; Level of need and services and supports required; Individuals removed from the waiting list during the past year by number and reason and length of wait; number of individuals waiting more than 90 days; and Annual data from the department of education about students with ID/DD including those graduating, those dropping out, and those turning 22 without graduating.

Greater amounts of detailed information and higher levels of transparency to the public are also important for a number of reasons. First off, individuals advocating for others and self advocates have access to information that appropriately educates them on the extent of the need. Next, families and individuals involved with a waiting list have a better understanding on when they may receive services. Also, legislators would be better informed of the problems and can use the information to adequately develop legislation, therefore making an informed decision based on current evidence. However, many states are not involved in these types of practices, which is seriously impeding their rate of improving the delivery of services to those in need. Lack of information also leads to difficulties developing data for the seven items previously mentioned in a nation wide analysis.

Following greater transparency of states' waiting lists, there should also be a system of prioritization and personalization implemented. The UCP believes that individuals approved for waiting lists should be referred to the same Protection and Advocacy Systems as those who are already receiving services. This move would allow individuals approved for waiting lists to have the same accountability as those already receiving healthcare based services. This idea would notify physicians caring for patients with Medicaid based funding that their clients are on a

waiting list and where they rank on the list. The Physician would then be able to provide insight

on the patient's condition and could help advocate for their patient's rank on the list, UCP

(2015). Personalizing the waiting list would only strengthen the powers aiding in the waiting list

reduction. The UCP believes that through placing human face/faces on these lists, people would

be able to finally see the distress these individuals are living with on a daily basis and hopefully

influence policy reform and a prioritization of funds towards these efforts. The final element to

the UCP's strategy to reduce waiting lists is to maintain persistence. Like all great change, these

efforts would take time and dedication. This study hopes to target some of these ideas and

address how current marketing strategies can aid in shedding light on many of the issues at hand.

CHAPTER 4

OPTION 1: CONVENTIONAL APPROACH

The first step in this process is to review the current approach being taken to deliver services to individuals with developmental and intellectual disabilities. Through today's technology, individuals, their family, and advocates can access the department of human services website through a quick Google search. Unfortunately, this action will only be triggered after an individual is displaying symptoms and signs of a disability. Many disabilities are easily identifiable, such as abnormalities at birth, however many disabilities are not as easy to identify, such as Autism Spectrum Disorder. Even individuals trained to identify the signs of Autism Spectrum Disorder can have difficulties, depending on the severity of the ASD. Individuals such as these can grow and miss many developmental milestones before being diagnosed. The first step to this process would be the primary care physician identifying an irregularity in an individual's actions and or development. This is also assuming that a primary care physician is seeing the individual regularly.

When an individual, an individual's family member, guardian, or advocate wishes to begin the process to request services, they are directed to the Department of Human Services (DHS) website. At this point, these individuals can begin to learn about the Prioritization of Urgency of Need for Services (PUNS) List, or what is also referred to as the waiting list. According to the Department of Human Services for the State of Illinois, (2017), individuals who are seeking services though PUNS will plan a meeting with a staff member from the Independent Services Coordination (ISC). The ISC agent will explain the state's definition of an individual with a developmental disability, and will also explain the details of how services are provided and what they can expect from the services if they qualify. This agency member will begin

collecting pertinent information about the individual, such as medical records, identification, Individual Education Plan (IEP), etc. If the family, or guardian cannot provide this information, they will then ask for consent to locate it on their own. This process can be delayed depending on how long it takes for the agency to locate the correct information. Once all of the information is collected, the ISC will then determine the severity of the individuals need for services. The categories of need for services are; Emergency: someone who needs immediate service or support, Critical: someone who needs services within one year, or Planning: someone who needs services in one to five years, DHS, (2017). The ISC will contact the individual or guardian by phone call or letter to re-determine the individual's category every year to see if their placement within a certain category has changed. Once the individual has been categorized and placed on the PUNS List, they will then be in competition with every other member on the list to receive available services. As this study has previously shown, an individual's ability to receive these services will greatly depend on which state they live in.

According to The Arc (2016) "On July 14, The House Appropriations Committee passed a fiscal year (FY) 2017 spending bill for the Departments of Labor, Health and Human Services, Education, and Related Agencies (L-HHS-ED). The measure provides $161.6 billion in discretionary funding, a cut of $569 million for FY 2016 and $2.8 billion below the President's budget." Through observing the data for the FY 2017 President's Budget, The Department of Health and Human Services, (2017), was budgeted $1,145 billion in outlays. This budget reflects an approximate $35 Million increase from the 2016 budget, and an approximate $17 Million increase from the 2015 budget. The budget from 2015 to 2016 had an approximate $17 million cut. Of this $1,145 Billion, 52% of the funds were allocated in Medicare, 34% to Medicaid, 8% to Discretionary Programs, 3% to Children's Entitlement Programs, 2% to Other Mandatory

Programs, and 1% to The Temporary Assistance for Needy Families (TANF). The Center for

Disease Control and Prevention (CDC), (2017), was budgeted $136 Million for programs under

Birth Defects and Developmental Disabilities. This number remains the same as the 2016

President's Budget, but is $4 million higher than that of 2015, and $7 million higher than that of

2014. Of this $136 million allocated to CDC programs $66 Million was allocated to Child Health

and Development, $55 million for Health and Development with Disabilities, $9 Million to

Hemophilia and Hemophilia Treatment Centers, $5 million to Public Health Approach to Blood

Disorders, and $2 million to Thalassemia.

CHAPTER 5

OPTION 2: ENHANCED CONVENTIONAL APPROACH

The current methods used to identify individuals with developmental disabilities, individuals seeking services, and individuals enrolling in PUNS and receiving services is working. However, as this study has shown, this is a work in process and needs to be improved to work more effectively. The issue lies in the fact that through government policy, more effective ways to approach an issue are not always the most efficient ways when considering funding. When observing the current way of operations, one could consider a more enhanced current option.

One way that the current procedures could be enhanced would be through frequency of evaluations. Children at a young age are screened through the educational system to identify young individuals with an intellectual or a developmental disability. This screening process is called The Developmental Indicators for the Assessment of Learning series, Third Edition (DIAL-3), Coughland-Mainard, (2012). DIAL-3 is the process of screening five developmental areas to identify developmental delays. According to Coughland-Mainard, (2012), These areas are required by state and federal law and incorporate; Cognitive Development (comprehending, remembering, and making sense out of one's experience); Communication development (the ability to effectively use and understand age-appropriate language); Physical development (fine and/or gross motor skills); Social or Emotional development (the ability to develop and maintain functional interpersonal relationships and exhibit age-appropriate social and emotional behaviors); and/or Adaptive Behavior (the ability to develop and exhibit age-appropriate self-help skills). This screening process can be an effective tool and allow students to be placed in a category of developmental disability if they score poorly in two or more developmental areas by

a one and one-half standard deviation, or at least two standard deviations below the mean in one or more areas. However, even within these five categories of testing, each category has its own sub categories. Which means that a child could perform strongly in the majority of a category's sub-categories, manage to pass that area, but could still hide an area of potential disability or delay, Coughland-Mainard, (2012). Therefore, increasing the frequency of administering the test and tracking specific data on each student as well as the data's correlation between categories and sub categories would be the only way to ensure that these tests are as effective as possible. If this process of increased DIAL-3 administration were to be taken into effect, many children would be identified with a disability or delay earlier in their life and educational career. These children would then be able to receive special education services through their school and an Individualized Education Plan (IEP), to assist in the child meeting educational milestones as closely to their peers as possible. This would also allow the education administration to identify a scope of the number of children they have in their system that require special services. As stated previously in this study, personalization is a main factor that needs to be addressed when improving the states ability to provide services. If more children were identified with a developmental disability, delay, or specific learning disability at a younger age and all around a similar point in their life, administrators, politicians, and the general public would see a greater need to provide these services to their children and their communities.

Although this enhanced way of identifying individuals with a disability at a younger age could see its benefits, is it even fiscally possible? According to Coughland-Mainard, (2012), the process of even administering the test a single time to an individual requires a large amount of resources. " Evaluations typically involve several highly-trained staff members, often referred to as specialist such as an occupational therapist, physical therapist, speech/ language pathologist,

audiologist, school psychologist, reading specialist, behavior specialist, or autism specialist who are in short supply and who have large caseloads of students requiring therapy during the school day" Coughland-Mainard, (2012). Along with all the personnel resources needed, these examinations can also require a considerable amount of time to be completed thoroughly.

CHAPTER 6

OPTION 3: PROACTIVE ENHANCED APPROACH… IMPLEMENTATION THREE A

MORE MODERN APPROACH

Perhaps a more logical and responsible approach would be to promote awareness. One way to promote awareness is to increase the exposure of information to the general public. An educational campaign on the facts of intellectual and developmental disabilities and the services available could be a very effective tool to help eliminate some of the issues and trends we are seeing throughout our analysis. In today's world, the most efficient way to spread information to a large group of people is through social networking and the Internet.

On March 7th 2016, Kit Smith published an article on a website called Brandwatch.com titled "Marketing: 96 Amazing Social Media Statistics." According to the article, as of March 7th 2016, the Internet has 3.17 billion users, and 2.3 billion active social media users. From a business perspective "38% of organizations planned to spend more than 20% of their total advertising budgets on social media channels in 2015." An article from WebStrategiesinc.com titled "How Much Should You Budget For Marketing In 2017" states that this number went up to 30% in 2016, and is expected to raise to at least 35% in upcoming years.

How effective can social media platforms be when it comes to reaching large numbers of individuals? Will the general population even respond to information based on a category such as healthcare? One way that we can review this idea would be to observe the data behind the social phenomenon of the ALS Ice Bucket Challenge. In July 2014 a group of ALS (Amyotrophic Lateral Sclerosis) organizations supported an act of online video challenges where challenged individuals were supposed to video themselves pouring a bucket of ice water on their head and then post it on social media, challenging others to do the same. The idea was that these

challenged individuals had twenty-four hours to complete the challenge and if they failed to do so they were to pledge a financial donation to ALS charitable organizations. Within one month the Ice Bucket Challenge was one of the top trends on social media. Media Analyst Jeremiah Owyang, Founder of Crowd Companies, collected data on the effectiveness of the ALS Ice Bucket Challenged. According to Owyang, (2014), approximately 2.4 million video were shared on Facebook in relation to the Ice Bucket Challenge, and as of Sept 22, 2014, the ALS Association had raised up to $114 million in donations.

Organizations in the private and non-for profit sectors are seeing great response to their efforts to spread awareness for individuals with developmental disabilities. On February 19, 2017, the Cerebral Palsy Foundation posted a video titled "ZACH ANNER'S TOP TEN ABOUT CP". The video is an informational comedy piece where Zach Anner, an individual with Cerebral Palsy, talks about ten things he wants everyone to know about CP. Since February 19 2017, two weeks from the point of this writing, the video has 13 million views, 186 thousand likes, 149,239 shares, and 11 thousand comments all on Facebook alone, and growing. The best part of this is that it is very inexpensive to create this type of media. Actually, anyone with a Facebook account can post videos for free. Free Sharable Content is original content that is free to post and be shared throughout social media. This content can be high quality and interactive. Many organizations will use free sharable content such as the Cerebral Palsy Foundation's video, with the intent that the interesting quality and production of the video will lead to successful high volume share. Free shareable content can also be used through all platforms of social media and is easily distributed through outlets such as Hootsuite. Facebook also offers advertising campaign options. These structured advertising campaigns allow the advertiser to boost specific advertisements and Facebook creates reports to the user on how specific ads are performing, as

well as to what clientele is reacting to the media shared. Facebook Business, the area of the

Facebook organization that manages their advertising platform, operates like much of the

Internet advertising world, through a Cost Per Click (CPC) and a Cost Per Mile (CPM) method

of charging for advertisements. FitsSmallBusiness.com, states that the Facebook Advertising

Cost by Industry is divided into the categories of: Automotive, E-Commerce, Education,

Entertainment, Food and Beverage, Professional Services, Retail, and Technology. For the sake

of this study, we would consider this type of campaign to fall into the Education Industry.

FitSmallBusiness.com states that, Cost Per Click is defined as the cost for 1 click to your

website, and within the category of Education this rate is $5.61 CPC. Cost Per Mile is defined as

the cost for 1,000 impressions, or views of your ad, which is set at a rate of $.044 CPM for

Education. Although Facebook Advertising Campaigns are a great outlet for exposure at a

reasonable price, many large organizations will proceed with their marketing through sharable

content due to the advantage to allocate resources into the production of media.

CHAPTER 7

ASSESSMENT AND RECOMMENDATION

The main focus behind these ideas is to enhance the way that we connect individuals with services, and ideally find a way to do so that is as cost effective as possible. As previously discussed there are different approaches that can be taken into consideration. The first approach would be to leave things how they currently are. This approach is currently reaching individuals and a lot of individuals with disabilities are receiving services. However, the data shows throughout this research that this needs to be improved. The second and third approaches are ideas that could aid in making this more of a possibility.

The second approach focuses on increasing the frequency of screening children for early signs of a developmental disability or delay. This would allow for children to be identified as an In-Need individual as early as possible. Through this these individuals could be receiving services such as Individualized Education Plans that would allow them to focus on their strengths and weaknesses through individualized education, and help them reach developmental milestones as close to their peers as possible. Ideally this would lead to these individuals becoming a much more productive member of society, where they could possibly maintain a job in the community, and require less aid and funding from the government for services. Although this approach sounds good in theory it would be very costly and require a large amount of resources. Even though full implementation might not be immediately possible, it is definitely a concept that should be worked towards through small measures.

The third implementation consists of ways in which we can work towards some of the concepts outlined in the second approach. The ideas in this approach should be taken into consideration as soon as possible. Advances in technology have allowed for the spread of

information through the Internet to become the number one marketing resource. Raising

awareness of developmental disabilities and the services available to these individuals through

online information sharing would be the most efficient tool possible. Advertising and sharing

information on the Internet and through social media is extremely inexpensive and has the

opportunity to reach the greatest number of people. Larger groups of people becoming informed

could lead to more individuals identifying the signs of developmental disabilities and delay in

children, which could aid in the same areas discussed in the second approach. This could also

lead to economic development and entrepreneurialism. Since there is a surplus of individuals on

health care based service waiting lists, this creates a large demand for services. If more

individuals began taking initiative to becoming service providers the numbers of these waiting

list would begin to decrease. This would also then begin to provide more jobs within our

communities, and overall increase economic development.

In conclusion, it is very apparent that much more effort needs to be taken when

considering the lack of resources available to individuals with developmental and intellectual

disabilities. This study identifies whom this population consists of and the historical background

surrounding these individuals within the United States. This study also reviewed the problems

we are currently facing within our country and analyzed how specific states are comparing

against one another on their ability to provided services to individuals with developmental and

intellectual disabilities. Furthermore three recommendations were presented on ways the

government can proactively support efforts to decrease the size of state waiting lists throughout

the country. Although there may be many more alternative ideas on how to decrease waiting

lists and better connect individuals with supported services, the ideas presented within this study

could be a greater step in helping these individuals. If the government would support public

policy and an educational campaign, waiting list could begin to shrink, individuals would begin

receiving better quality of service, and more individuals within the community would have

access to the knowledge they need to advocate for individuals with intellectual and

developmental disabilities.

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　　　THREE ALTERNATIVE REFORMS TO IMPROVE SERVICES AND DECREASE
　　　WAITING LISTS

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