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Adult autism policy: An analysis of current policy and legislation in the US

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ADULT AUTISM POLICY: AN ANALYSIS OF CURRENT

POLICY AND LEGISLATION IN THE U.S.

by

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Bachelor of Science
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A thesis submitted in partial fulfillment
of the requirements for the

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ABSTRACT

Adult Autism Policy: An Analysis of Current Policy and Legislation in the U.S.

By

Maren Bennett

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The topic of autism has been gradually emerging as a primary focus for research, education, charities, etc. Much of the attention has been centered on children; however, the subject of adults with autism has long been overlooked. Adults with autism need policy improvements to help gain as much independence in their daily lives as possible. It is the purpose of this thesis to identify deficiencies in service delivery and recommend policies to improve the quality of life of adults with autism. I will utilize a cross-sectional multiple case study design. Three private foundations are utilized as the case studies, along with interviews of elites associated in or around these organizations as well as in state government. Previous literature and policies will be reviewed and integrated into the research garnered from the case studies. Following, the information will be synthesized, using John Kingdon's model of Multiple Streams, into viable policy recommendations.

TABLE OF CONTENTS

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I would like to acknowledge my wonderful family for all the support and enthusiasm during this project, especially my little brother for the inspiration. I would also like to acknowledge the autism community as a whole for their tireless efforts and undeniable passion; including all of those wonderful people who sacrificed a little time to talk to me and share their dreams. Thank you to all my friends who were always there to listen to my ideas and for all the great advice. Lastly, I would like to recognize my committee, graduate advisor, and diligent administrative assistants, without which, I would not have been able to make it this far.

CHAPTER ONE

INTRODUCTION

In 2000, nationwide spending on programs for people with severe disabilities reached $29 billion, including $22 billion for community services. The same amount was spent on the purchase of Coca Cola products. –Opportunity Village, 2008.

The topic of Autism Spectrum Disorder, henceforth referred to as autism, has been slowly coming into the realm of general research, whether it refers to policy, genetics, services, or education. However, this focus on autism has been primarily dominated by research or legislation for children. Analysts seek to find new diagnostic methods, new behavioral programs for the very young, directing them into the proper programs quickly such as early intervention. Children are more accessible and identifiable, therefore, it is less challenging for researchers and advocates to get funding or policies passed.

Regrettably, a massive population with autism continues to be overlooked. Children with autism will grow up one day and they are going to be entering an age where there is very little support or attention. These children will become adults and will be forced to leave their public or private schools. It is likely that people with autism will need support and care for the rest of their potentially long lives.

Adult populations are often not attractive causes. Children, by contrast, attract attention. The public is influenced by media flashes of children being abused, harmed, or disadvantaged. Adults are no less vulnerable however they receive much less attention.

The government feels obliged to supply money, policies, and support for school aged children and young adults, but ceases to give that financial support once "graduation" commences.

State and federal governments need a more active role in adult autism policy. This population is no less needy or deserving than the children they once were. This study will analyze the effectiveness of current U.S. legislation by way of a multiple-case study. I will reveal those needs that are not being met and propose recommendations for future policy. It is the hypothesis of this thesis that the current policies are not effective in meeting all of the needs of adults with autism. My research will employ interviews of elites in the autistic and legislative communities as well as in three organizational case studies to exemplify what the needs are and if they are being met adequately. These foundations and organizations are all grounded and based off policies. They are regulated by current policies and therefore policies that are more specific will help enable organizations such as these to thrive, as well as many more to be created.

What is Autism?

Autism Spectrum Disorder is a highly complex developmental disability. It is a "result of a neurological disorder that affects the normal functioning of the brain, impacting development in the areas of social interaction and communication skills" (Autism Society of America [ASA], 2007). It is a spectrum disorder meaning that it affects individuals differently and with varying degrees of intensity. Most individuals with autism "typically show difficulties in verbal and non-verbal communication, social interactions, [gross motor skills], and leisure or play activities" (ASA, 2007).

Autism is fast becoming a nationwide concern. Within the last ten years, the prevalence of autism has risen several hundred percent; it has become the fastest growing developmental disability in the nation, resulting in a 10-17% annual growth (ASA, 2007), and the once unknown and unfamiliar disability has become the new focal point for many organizations and foundations. On February 9, 2007, the Center for Disease Control and Prevention released its Morbidity and Mortality Weekly Report. In this report, it now estimated that the prevalence of autism is now every 1 in 150 births will have a form of the developmental disease. Also, it includes that 1 in every 94 boys will have autism, an unaccountable phenomenon. The CDC had previously estimated the prevalence at 1 out of every 166 births in 2004 (MMWR, 2007).

Outline of Study

This thesis will utilize a cross-sectional multiple-case study design, using the case study methodology as described by Yin (1994), to analyze the effectiveness and implementation of current policies and practices. I chose to utilize a multiple-case study instead of a single case study to eliminate any "unique" or "rare" cases in which the date would not be generalizeable to the disabled population. In addition, with multiple-cases, the results will be more robust or compelling (Yin, 1994, p. 45).

The units of analysis will be three private organizations catering to autistic adult clients in California, Nevada, and North Carolina. These three states were chosen due to prominent service organizations and the variation in the size of the state population. Since this thesis cannot study each individual state, these three states will represent the highly populated (represented by California), average or median populated (represented by North Carolina), and below average population (represented by Nevada) states.

I have chosen to look at private foundations as examples of public policy because each organization is a succinct entity implementing many facets of public policy into services for a wide variety of disabled clients. Private organizations still have to abide by public policy; however, they are not as constrained by minimal public budgets. Public services are recognized for lack of funds to efficiently deliver services. Clients of public services not only have the hardship of their disability, but it is then compounded by the complexity of highly inadequate resources. With the lack of these resources, be it money, space, or staff, it contributes to negative behaviors and the regression of the client's abilities. Not to say private foundations have a plethora of funds; it is only to say that they receive more funds from various places.

Although both public and private organizations receive state and federal dollars to operate, private foundations are not restricted to only government funds; they also receive donations. With these donations, private organizations are allowed to enhance their services in ways public ones cannot afford. As an example, private foundations can offer slightly higher wages to its staff, which could then potentially bring in a higher quality worker. In addition, private organizations do not always have the same overhead expenses found in public services. It is more common for a large donation, such as a building or vans for transportation, to be given to a private foundation than a public one. Private foundations give a more lucid glimpse into the lives of disabled individuals and the services they require, thereby facilitating my research in order to provide accurate policy recommendations.

In conjunction with a more succinct glimpse and purportedly higher funds, I have chosen private foundations because the states themselves contract out to these

organizations to provide services to the population. The states can not afford to provide all the services and programs necessary to meet the demands of this ever growing population so they must rely heavily on outside agencies. This does result in more decentralized authority and service delivery, however, some states have implemented state funded regional centers to help coordinate between such private agencies. Regional centers, as discussed in further detail in Chapters Three and Four, are state run organizations that provide programs and coordinate services for individuals with disabilities, as well as contract out those services it is not able to fill to outside, private organizations. It is for all these reasons why I have studied private organizations as opposed to public ones.

The case studied in California is the California Autism Foundation (CAF) in Richmond. This private organization explicitly caters to the needs of over 200 adults with autism, 300 clients total, and is a perfect candidate for this study. As an exemplary organization, CAF runs day programs for constituents with autism and other developmentally disabilities. It owns numerous residence homes throughout the Bay Area for those adults needing supported living, as well as those adults who need one-on-one care at all times. It also provides vocational training and job opportunities for its constituents as well as transitioning school-aged students from their private school on the grounds into the various opportunities available.

The case studied in Las Vegas, Nevada is Opportunity Village. This non-profit organization caters specifically to adults and currently serves roughly 3000 clients. The main purpose of this foundation is to provide adults in the southern Nevada area with job opportunities and a way to give back to their community. It runs a vast job network and

has found work for many individuals with developmental and physical disabilities. This organization helps take the burden off of the state by allowing these special citizens a chance to work and improve their daily life. This organization differs from CAF because it does not offer residential assistance and is primarily focused on job opportunities.

The third case study is the Easter Seals UCP foundation of North Carolina. This organization is similar to CAF because it offers housing supports, as well as job opportunities. Easter Seals UCP serves a much larger population than CAF or Opportunity Village. It is part of a nationwide foundation however; this particular organization is quite extensive. It caters to roughly 15,000 clients and offers job placement and training, housing assistance, day programs, transportation, referrals, advocacy, and more.

These cases exemplify adult services in their respective states and will provide vital information for the identification of needs as well as what is currently being done to address those needs. The organizations will provide the necessary information regarding what adults need, how much it costs, how the services are implemented, what necessities are needed to run such an organization; all to further prove what policy and legislation must address.

The three organizations vary in number of clients served and the range of services offered. However, the focus will not be on these differences; it will be on the similarities. These organizations represent their particular states, in different parts of the country, all serving similar types of individuals. The fact that they differ so much from each other yet still experience the same needs show that this phenomenon is not a case-by-case or state-by-state experience, but that needs of disabled clients are the same across the board. The

needs of an autistic adult will be the same no matter in which state s/he lives. Autism is the same no matter where the individual is from. Therefore, the varying sizes and service capacity of these organizations pale when compared to the emergence of similar needs throughout. My research will show that no matter the size of the organization, its location, or which services it offers, they all still need more help.

Research will then delve further by analyzing information from interviews a number of individuals who are involved with or particularly knowledgeable about specific aspects of the programs, policies, or autism including administrators, advocates, service providers, legislators/policymakers, etc. The interviews will be conducted in person, when applicable, and via telephone. The themes of the questions for the interview will involve implementation of policies into practices at the various organizations; the needs of the population that are not being met or addressed; what obstacles are present in the allocation of needs; as well as what changes these experts would want to bring about for adults with autism on a whole.

Regarding the legislators and policymakers, the themes for these questions will involve topics such as what legislation is now being debated regarding adult autism; what is the trend of policies being passed or discussed (concerning this population); what pieces of legislation or policies have been most beneficial previously; as well as recommendations or directions for future policy. All of the interviews and research will be conducted according to the guidelines set forth by the Office for the Protection of Human Subjects, 45 CFR 46 and the approved Research Proposal.

In conjunction with the case studies and interviews, this thesis will make use of a literature review as well as a policy review to contribute to the general knowledge of

policy and trends operating in this community. The literature review will be an analysis

and commentary on the relevant literature related to this topic. The policy review will

describe and analyze national policies and legislation, including but not limited to, the

IDEA and ADA policies currently active.

Subsequently, utilizing John Kingdon's Multiple Streams model theory, the data

and research will be synthesized into recommendations for future policy regarding the

needs of adults with autism. This community has been overlooked for too long. The rise

in the number of children with autism only proves that this population will be growing,

just as exponentially as the birth rate. It will be too late to start change when this boom

hits adult age.

Following the case design illustrated in Yin (p. 49), after developing the theory

for the study (Multiple Streams), I selected the cases (three organizations) and the data

collection protocol (literature review, policy history, interview research protocol). I then

conducted each case study, researching each organization extensively along with the

interviews. Subsequently, I wrote a report for each organization, located in Chapter Four.

Finally, I drew cross-case conclusions, modified my theory where appropriate, and

developed policy recommendations.

<div align="center">Multiple Streams</div>

The model used in this thesis to make policy recommendations is John Kingdon's

Multiple Streams framework (Kingdon, 1984; 2003; Sabatier, 1991; Stout & Stevens,

2000; Zahariadis, 2007). This theory implements three 'streams' of processes in order to

analyze and implement policy. These are problem recognition, policy

formation/community, and politics. Initially, a problem is presented that has captured the

attention of those integral actors in the government. The actors can be various politicians including the president, interest groups, congressional staff, lobbyists, bureaucrats, policy entrepreneurs, as well as non-governmental actors such as the media, academics, researchers and consultants. Second, a community of specialists will concentrate on policy proposals and alternatives. Lastly, the political stream is composed of various notions as "swings in national mood, vagaries of public opinion, election results, changes of administration, shifts in partisan or ideological distributions in Congress, and interest group pressure campaigns" (Kingdon, 2003, p. 87). The events listed in this stream occur independently of the other two streams. When a policy window or opportunity "opens", these three streams, if worked carefully and effectively, come together and a policy can then be passed.

Conclusion

The Multiple Streams model demonstrates a realistic way of policy formation in the U.S. today. This thesis will utilize this particular model to assist in illustrating the necessity of policy improvement for the adult autistic population. I argue that the policy window for adults with autism is currently open and I will identify each stream independently and then couple the three streams together in order to make viable recommendations for policy change.

Autism is identified as a legitimate problem by way of feedback, national mood, and indicators. I argue that the prevalence of autism as a widespread topic in the media, news, and celebrity charity events cannot be denied. Along with this undeniable exposure, the topic has also been addressed by Congress in its debates and discussions. Therefore, I assert that the subject of autism has had ample time of "softening up" and the

political actors have become aware of the problem and are now comfortable with addressing policy change. Finally, synthesizing the political stream with the current political atmosphere, I contend that the timing in the political arena is right for policy action. A new administration will take place by the end of the year, allowing for a very fortuitous policy window to be open and a chance for new policy to be enacted. In summation, I argue that the timing is right for swift and efficient improvements to the current adult autism policies and that my research has led to feasible recommendations for such improvements.

In addition to Kingdon's Multiple Streams model, the case studies and interviews are used for qualitative purposes and are employed to obtain a better understanding of the community as a whole. They are used to observe the various processes involved in providing essential care to the disabled and to provide a declaration of needs; all in order to illustrate the generalizations needed for policy recommendations.

CHAPTER TWO

LITERATURE REVIEW

The topic of policy for adults with autism, let alone autism policy, has only just

been tapped into within the last three decades; thus, it has many different avenues for

research not yet identified. I have selected a range of articles with an assortment of topics

to convey the disparate views in the disability community. Each section has a compilation

of articles of similar salient themes. The following sections represent the important

factors I believe are necessary to aid my research. Following the research articles, I have

examined Kingdon's Multiple Streams theory and discussed its various components. I

end this chapter with my general argument along with my expectations of what my

research may find.

Program Effectiveness Studies

Many articles focused on analyzing services and programs already in existence

(Appendix, 1996; Bennett, Wood, & Hare, 2005; Heller, Miller, & Hsieh, 1999;

Kennedy, 2001; Upshur, 1983). Heller's, et al. article researched the effectiveness of an

Illinois based support service for families with a disabled member. The Home Based

Support Services Program was designed to assist families with adult members with

severe mental and developmental disabilities. The service facilitator helps the family or

individual devise a "service plan" or package of goods and services costing up to $1,374

per month. (Heller, Miller, & Hsieh, 1999, p. 420). Heller, et al. attest to the need for system-wide consumer directed family support programs for adults with developmental disabilities and their families. Such programs need to be expanded so that they can serve all families that meet the criteria for the program.

Using a "questionnaire compiled from original and existing instruments" (Heller, Miller, & Hsieh, 1999, p. 422), the researchers were able to show families enrolled in these services had fewer unmet needs than those families not enrolled. With their questionnaire, the researchers were able to describe the most unmet needs of families with disabled members. Using a control group and a participant group, the researchers were able to parse out the four highest unmet needs out of a list of twenty-nine for those families not enrolled in this service. For the control group, the four highest unmet needs were the lack of information about obtaining residential services (47%), social recreational activities (43%), advocacy (38%), and in-home respite care (36%) (Heller, Miller, & Hsieh, 1999, p. 425).

The participant group, families that were enrolled and receiving funds from this program, was generally able to use their family support funds to pay for and access in-home respite care (67%) as well as social recreational activities (45%). In addition, about half of the families used the funds to pay for transportation services that likely increased the social-recreational opportunities for the adults with developmental disabilities. Some participant families, however, were still not able to obtain all the respite (12%), social recreational (21%), and transportation (10%). The major reason cited was the lack of available providers (Heller, Miller, & Hsieh, 1999, p. 425).

Another study, based in the United Kingdom, also used a questionnaire in order to assess individual needs and services being met. In the area where this study was being conducted, there were no formal specialist services for individuals with autism. The researchers discussed how effective learning disability services were in meeting the needs of those autistic patrons. The discussion was whether or not such a service met the majority of needs.

In this study, fifty-nine questionnaires were distributed to service recipients and forty-six were returned. The questionnaire asked the service recipient to identify their level of need for assistance in "daily living activities or level of disability and nine items covering types of challenging behavior" (Bennett, Wood & Hare, 2005, p. 59). With the results of the questionnaire, researchers divided recipients into three different categories: Autism diagnoses, high scorers without diagnoses, and low scorers. High or low scores pertain to those scores attained by the questionnaire. High scorers exhibited many autistic traits without having an official diagnosis of autism. Low scorers exhibited few to no autistic traits. They then compared the three groups on "specialist and general service provision" (Bennett, Wood & Hare, 2005, p. 60).

Specialist provision included whether staff received training on autistic spectrum disorders, whether the training was specific to the individual, or if the staff had knowledge of autism or had access to information on autism. It was found that there were no differences between groups in terms of specialist provision. In terms of general service provision, individuals with autism diagnoses received more services than the low scorers. The researchers determined that having had training on autistic spectrum disorders did not make a difference in terms of knowledge of autism (Bennett, Wood & Hare, 2005, p.

60). The hypothesis that the autism diagnosed group would receive more specialized services than any other group was not supported. However, this group did receive more "service input overall than the low scorers group" (Bennett, Wood & Hare, 2005, p. 61).

The researchers did find that the most efficient services for adults with autism would be an individually based program. They observed that the services in this particular program were carried out on a needs-basis rather than on a diagnoses driven agenda, which ended up being more beneficial to those having challenging behaviors without a specific diagnoses. The article concluded that any service program should be needs based rather than diagnostically based (Bennett, Wood & Hare, 2005).

The Wells, Sandefur & Hogan article focused on individuals with disabilities and their transition to "adulthood". The authors use a broad sense of the word adult to determine whether or not their subjects have yet attained the status of adulthood. The definition of adulthood, in this article, included attainment of high school graduation and enrollment in post-secondary school, competitive employment, residential independence, and family formation (marriage and parenthood). (Wells, Sandefur & Hogan, 2003, p. 807).

Similar to the findings of other research, Wells, et al. stated that "sociologists have paid almost no attention to those individuals with disabilities who are making the transition from late adolescence to full participation as adults in American society" (Wells, Sandefur & Hogan, 2003, p. 804). The researchers noted that there is little current investigation regarding those young adults with disabilities successfully, or not successfully, making their transition into adulthood. They cited that "approximately one-fifth of the non-institutionalized population of the U.S. has some form of physical or

developmental disability…and slightly more than 6 million children are enrolled in federally supported educational programs for those with disabilities" (Wells, Sandefur & Hogan, 2003, p. 804). Their main argument is that the number of adolescents in America that have some form of disability is high enough to warrant exhaustive research on the probabilities of success of transitioning into adulthood. They maintain that this should be a major public issue.

Needs Based Studies

Other articles used sociological approaches to help explain the urgent needs of this community, ranging from daily activities, respite care, or the transition into adulthood (Scotch & Schriner, 1997; Upshur, 1983; Wells, Sandefur & Hogan, 2003). Scotch and Schriner's (1997) article discussed two distinct models used to implement disability policy. They discussed the "minority group" model and the "human variation" model in order to approach implementing policy. The authors used these models to further exacerbate the necessary needs of a minority group, such as those with disabilities, and a way to go about recommending policy. These models will be discussed in further detail in the model theory section.

Upshur's article (1983) discussed the urgent need of respite care for disabled people and their families. Respite workers help relieve families of everyday stress of living with a disabled individual by assisting the individual with daily activities and allowing the family a break. In the literature, and among families, this was one of the most unmet needs of families with disabled members (Heller, Miller & Hsieh, 1999; Upshur, 1983). Respite care has been shown to help relieve stress of the parent or

caregiver, thereby preventing things as abuse, neglect, and institutionalization of the disabled individual. It is an important asset to these families; however, it is not as widespread or reliable as is needed (Upshur, 1983).

Respite care, due to the fact that it is considered an in-home service, is not widely available or a common part of community services assisting individuals with disabilities. Upshur used a survey of twenty four states and only nine states had a policy and funding for some type of respite program. These states included California, Connecticut, Idaho, Montana, Nebraska, Ohio, Oregon, Pennsylvania and Massachusetts. Delaware had a respite program that was organized through its state hospitals; however, there were neither specific state funds nor guidelines regarding respite and its delivery (Upshur, 1983, p. 14). The author found that even in those states where a respite program was developed, individuals with severe behavioral problems, those needing adaptive equipment, and those needing special feeding techniques were often excluded from these services. The author pointed out that these "families [that have] the greatest need for relief are most often left with few alternatives" (Upshur, 1983, p. 15).

Upshur then develops four categories of respite care delivery. These have been identified through surveys Upshur mailed out in Massachusetts and Indiana, as well as the other eight states mentioned above. The first of which is the Home-Based Care model. One of the most common delivery systems for this is basically an agency that uses trained respite workers (similar to babysitters) to provide respite on a day to day basis, sometimes overnight or for a short extended period, i.e., the caregivers take a vacation. These respite workers will generally watch the individual in the client's home. This model is quite cost effective since the majority of funds are spent on the respite provider

who is only paid when services are delivered. Aside from training costs, there are virtually no other fixed costs. A limitation of this type of program is that some families may not feel comfortable with a non-professional respite worker. Some disabled individuals may need to have a professional in charge of their care, such as a nurse or hospital worker, e.g. someone with specialized and intensive training, as opposed to the minimal training a respite worker endures. Also, a block of respite care is not scheduled for a long period of time, perhaps a week or two at the maximum, especially for overnight care. It is for a temporary relief, not a daily service.

Under the Home-Based Care model, other options for respite are available. The "funding conduit" (Upshur, 1983, p. 16) gives the family the responsibility for providing the respite worker and then the agency reimburses the wages to the family. This is the least costly model. There is no training fee since the family finds the provider from outside of the organization. A third option for respite care under this model is the respite care home. As the name suggests, it is a home or apartment where the worker is stationary and the individuals needing care are the ones to travel. This form of care was conceived as an alternative to institutionalization. Finally, the fourth option under the Home-Based Care model is the individual provider. A person, who is unaffiliated with a particular agency or hospital, runs his or her own respite service. This lacks similar safeguards as the funding conduit model. There would be a problem of training or monitoring as well as backup.

Other less common models for respite delivery include Group Day Care and Residential Care. These models are relatively self-evident. These models provide for a highly structured environment outside of the client's home and can provide benefits such

as socialization, trained staff, emergency relief, etc. A negative aspect to these models is that they are both much more expensive than any home based respite.

In addition, Upshur combined everything else that may be construed as a respite program into an adjunct services category. These include "community residences [...] residential treatment facilities, nursing homes, and long-term state institutions" (Upshur, 1983, p. 18). These facilities shy away from the goal of the prevention of institutionalization of the disabled individuals. These would be a sort of last resort for families needing respite.

Uphsur's argument was that respite care for families with disabled members was, and remains today, a vital priority to the disability community. The value of respite care to the family cannot be underestimated. It remains one of the most important needs of families throughout the country. Although respite care is considered an in-home based service and will not be discussed heavily in this thesis, it is acknowledged how important and necessary this need is to families and one would hope other policy analyses will continue to work on bringing this problem into the policy arena.

Kennedy's article focused on the varying needs people with disabilities have on a daily basis. This article discusses the unmet and under-met needs of adults with disabilities (non-developmental) for activities of daily living (ADL) as well as instrumental activities of daily living (IADL). The population the author focused on consisted of elderly adults perhaps with age onset disabilities, as well as those individuals with physical disabilities. The needs the author addressed, however, can be used in reference to those individuals with developmental disabilities.

The categories of needs for ADLs are bathing/showering, getting outside, dressing, walking, transferring, using the restroom, as well as eating. The IADLs consist of doing heavy housework, shopping for groceries, transportation, preparing meals, doing light housework, managing money, managing medication, and using the telephone (Kennedy, 2001, p. 1308). Obviously, these are all home based services. The purpose of this article was to determine the rates of needs assistance and to identify particular factors associated with unmet and under-met needs. This will help define disability support deficits and be able to inform policy makers where to aim their efforts.

Kennedy used the Adult Disability Follow-Back Survey (DFS-A) which was a supplement to the 1994 and 1995 National Health Interview Surveys (NHIS) (Kennedy, 2001, p. 1306). The survey asked the respondent if they "had any difficulty with the activity [ADLs or IADLs] because of a health or physical problem" (Kennedy, 2001, p. 1307). Of those that responded that they did have a difficulty, they were then asked a "series of question about whether they received personal assistance" (Kennedy, 2001, p. 1307). Their response was broken down into four types of assistance need: no need, unmet need, under-met need, and met need. Approximately 10-20% of respondents who identified a need for assistance in an ADL or IADL also responded that help with that need was unavailable or inadequate.

Kennedy contended that living alone was the strongest predictor of a need that was under-met or unmet all together. It was then recommended that a family tax credit or incentive to help offset the costs of caring for a disabled individual would be able to decrease the numbers of disabled people living on their own. Also, a mix of formal (institutional or state run service) and informal (respite service) care would also help

decrease the odds of unmet and under-met needs for those adults who rely nearly exclusively on unpaid assistance (Kennedy, 2001).

With so many varying topics concerned with disability in general, it is hard to find literature with specifically relevant information for this topic. That is, literature focusing on adults with autism or other developmental disability and their specific needs and obstacles related to providing care. However, one thing is very clear. More research is needed and this work hopes to bring identified unmet or under-met needs for this specific population to the forefront of policy and legislative debates in order to enact change.

Model Theory

Minority Group Model

There are various theories in the literature with regards to the best way to approach policy change or policy making. A common model for policy theory is the minority group model (Hahn, 1985; Scotch & Shriner, 1997; Bickenbach, Chetterji, Badley, & Ustun, 1999; West, 2000). This model argued that people with disabilities have historically been discriminated against, much like other minority groups such as African Americans and women. They are "subject to prejudiced attitudes, discriminatory behavior, and institutional and legal constraints that parallel those experienced by ... other excluded groups" (Scotch & Shriner, 1997, p. 149). Individuals with disabilities have been "subjected not only to stereotyping, but also to stigmatizing, which has made them the targets of aversion and ostracism" (Hahn, 1985).

The minority group model strived to reach beyond an individual level of analysis and focused more on policy objectives and institutional change. This model concentrated on how the "personal experience and social meaning of disability are the consequences of culture, institutions, and the built environment" (Scotch & Shriner, 1997, p. 151). It went beyond individual struggles and focused on adapting the environment to better accommodate this group. By defining the politics of intergroup relations, the minority group model greatly helped to define a group stigmatized by society for their natural characteristics, and searched for policies and legislation to define and solve the problem.

Human Variation Model

Another approach to the politics of disability is the human variation model. This model attempted to take the minority group theory a step further. Scotch and Shriner (1997) contended that while the minority group model had been responsible for much of the change seen in disability politics and policies over the last few decades, it was still in need of an additional underlying theoretical perspective. The minority group model focused most of its energies on achieving "equal treatment but does not guide the employer in designing accommodation beyond demanding the moral equivalent of equity" (Scotch & Shriner, 1997, p. 157). The authors contended that:

> By characterizing all barriers faced by people with physical and mental impairments as discrimination, we risk trivializing the still prevalent and often vicious stereotyping and exclusive practices by confounding them with the general incapacity of social systems to respond to individual variation (Scotch & Shriner, 1997, p. 156).

The human variation model sought to address disabilities on a more individualized basis. The human variation perspective, as Scotch & Shriner (1997) described, suggested that the lack of access to employment by persons with disabilities should be resolved by maximizing each individual's productivity rather than demanding the legal entitlements of equality. This perspective contended that "employers [should] view individuals as potential contributors rather than as members of groups whose legal status threatens the autonomy of business judgments" (Scotch & Shriner, 1997, p. 158). A sound contention the authors had for the minority group model stated that "many people with disabilities have problems functioning [however,] that will not disappear even if prejudice and discrimination are eliminated" (Scotch & Shriner, 1997, p. 157).

Dowrick and Keys (2001) would agree that the minority group model was hampered by a narrow view. They posited that "the disability rights movement has become increasingly concerned with civil rights rather than with the development of services for people with disabilities" (Dowrick & Keys, 2001, p. 3). These authors oppose the minority group model, as interpreted by their attitude toward the diverging interests of the disability civil rights movement. Dowrick and Keys asserted that advocates, as well as members of this movement, "have rejected approaches that focus on individual deficits and impairments, and have instead called attention to the social, cultural, and political barriers and the frequent lack of fit between individual abilities and contextual demands faced by [these people]" (Dowrick & Keys, 2001, p. 3).

This attitude, as expressed by Dowrick and Keys, to a certain extent, was contentious with the human variation model. Researchers associated with civil rights have agreed there are some short-comings of the minority group model, however, their

opinions deviate when the importance of individual attributes became viable. Although human variation put emphasis on individual accommodations, Dowrick and Keys suggested that focus should be on resolving barriers and contextual demand that were inhibiting independence of individuals with disabilities.

Michael Oliver would also agree that the minority group model, though successful, had the potential to represent the disabled community as a great victim of social prejudice. Oliver posited that if "disability is defined as social oppression, then disabled people will be seen as the collective victims of an uncaring or unknowing society rather than as individual victims of circumstance" (Oliver, 1997, p. 2). Oliver contended that if society were to perceive disabled individuals as poor, hapless, victims, social policies would be geared toward alleviating oppression rather than encouraging independence. It is in this direction, toward social and functional independence, that policies should be constructed (Oliver, 1997).

As acknowledged by the minority group model, individuals with disabilities were often met with discrimination. This discrimination can be from other individuals in society as well as from architectural or technological obstacles. West (2000) described discrimination against differently-abled citizens in two parts. The first, and arguably the most complex and prevalent, being prejudice. The U.S. Commission on Civil Rights in 1983 described prejudice as an attitude held by many people in society that "distorts social relationships by overemphasizing some characteristic, such as race, gender, age, or disability" (U.S. Commission on Civil Rights, 1983, p. 22). Other minority groups such as women, African Americans, individuals of Irish descent, etc. all have shared the

experience of prejudiced attitudes and some form of discriminatory practices in their lives.

McCluskey (1988) also contended that prejudice was one of the biggest obstacles individuals with disabilities faced. She argued that although so many disability laws and policies have been enacted in the pursuit to end discrimination, similarly to sex and race discrimination policies, lawmakers have been interpreting these policies differently. With anti- race discrimination policies, policymakers and the courts have established laws to combat the prejudice those minority groups have encountered. Interpretation of those laws would seek to indicate that the primary catalyst for discrimination towards race or sex, was prejudice. However, McCluskey argued that lawmakers were not interpreting the theme of antidiscrimination policies for the disabled as a way to end prejudice. She maintained that disability discrimination laws were being interpreted in terms of physical or mental difference, not prejudice. The author asserted that lawmakers "assumed that physical difference, not prejudice, is the primary problem...however, [it is] prejudice [that] is central to the problems faced by the people with disabilities" (McCluskey, 1988, p. 864) today.

Disparate Impact Model

Prejudice has contributed to the inception of yet another discrimination theory. The disparate impact model of discrimination hinted to the subtle effects of prejudice towards the disabled community. This theory was developed as a reactionary model for antidiscrimination policy and law. Again, it was used primarily for race and sex discrimination, but authors contend that its use towards disability discrimination would

help the pursuit of change spearheaded by disability interest groups (Jolls, 2001; McCluskey, 1988).

The antidiscrimination model, in which disparate impact was applied in reaction of, was the equal treatment principle. Generally, this principle, as used for gender and race discrimination, held that those individuals in similar situations must be treated alike. The civil rights movement for racial equity pursued equality in everyday life. It was the intention of this group to be treated *like everyone else* and no differently. The goal was to get society to *forget* the color of one's skin, or to *ignore* the fact that one is a woman, in order to be treated equal. As various authors have noted, it was not in the best interest of people with disabilities to have their special needs forgotten or ignored (Jolls, 2001; McCluskey, 1988; West, 2000).

While the allowance of opportunity for those victims of racial and gender discrimination was a goal, this passive toleration did not do anyone with disabilities justice. For the disabled community, it was a recognition of impairment and agreement of accommodation that was most necessary from society. The environment cannot just be left open, it must also be adapted.

An example of an allowance of opportunity without any real ability of use would be stairs on a bus for a person in a wheelchair. Just because individuals with disabilities are allowed to use the bus does not give them the ability. Equal opportunity to use facilities and technologies, such as a telephone, does not mean everyone has the equal *ability*. Disparate impact model contended that it is the job of society to accommodate those needing accommodation. As equal treatment was designed to eliminate discrimination based on race or gender, disparate impact suggested not only this but

extended beyond "equal treatment to reach subtle forms of prejudice and the effects of past unequal treatment" (McCluskey, 1988, p. 866).

McCluskey acknowledged a view that accommodations for disability could be provided for with separate programs, parallel to existing programs for *able-bodied* people. She argued that "this trend in disability discrimination doctrine is based on flawed assumptions about the problem of difference" (McCluskey, 1988, p. 868) and the disparate impact model would work to fix such assumptions. This trend also triggered memories of another "separate but equal" problem the government has dealt with in the past.

The 1896 Supreme Court case of *Plessy v. Ferguson* basically stated that segregation based on race was constitutional if the facilities in question were of equal quality. Years later, this in and of itself, was found to be inherently unequal. The important aspect of the disparate impact model is to eliminate these subtle prejudices and accommodate a single facility or program for the equal *use* by all citizens; not the inception of two separate but equal programs (Jolls, 2001, p. 652).

It was section 504 of the Rehabilitation Act that had incurred the most wrath from disparate impact theorists and advocates (Jones, 1991; McCluskey, 1988). Originally, section 504 simply mandated equal treatment of people with disabilities. However, as proved earlier, this did not address particular obstacles and disadvantages encountered by those with disabilities. Therefore, as scholars have acknowledged, "reasonable accommodations" have now been prescribed in all disability policies. McCluskey contended that "instead of approving special, segregated services, courts and policymakers should...require that unjustified policies with harmful effects be changed as

a whole, rather than remedied through separate policies targeted at the adversely affected groups" (McCluskey, 1988, p. 879).

As mentioned earlier, West (2000) described discrimination in two parts. The first being prejudice, which has been discussed in some length; and now the second aspect of discrimination: barriers. She defined barriers as "any aspects of the social or physical environment that prohibit meaningful involvement by persons with disabilities" (West, 2000, p. 7). Examples of barriers are stairs, for people in wheelchairs; the lack of Braille transcriptions for visually impaired students; or the lack of telecommunication devices (TDD) for someone who is hearing impaired. She posited that these barriers generated an "accommodation imperative" (West, 2000, p. 7). West noted that without the accommodation imperative, there could be no notion of equal opportunity for persons with disabilities. As mentioned above, an opportunity is not equal if the individual has no way of access or accommodation. In order for an opportunity to truly be equal, "more is required from society than a passive commitment to equal opportunity"(West, 2000, p. 7).

The common theories of disability politics, as discussed in this section, have been implemented and generally successful in making progress for the disabled community. The fact that there are so many varying models is, however, disheartening. There is not a single comprehensive model to answer the shortcomings of disability policies. There is no consensus on a single train of thought in the literature. Scholars are constantly finding areas in which previous models have lacked strength. Researchers have identified where other models have failed. Further research and scholarly work needs to be done to identify a single, comprehensive model or theory for disability policy. To find such a

model is where future direction of disability policy studies should be aimed. The disability movement has accomplished quite a lot in the last few decades, but continuous improvement is still necessary.

Policy Change Studies

Political Feasibility

How politically feasible is adult autism policy on the national level? When discussing political feasibility, one is referring to the probability of success a policy has of being enacted or implemented. How likely is it that this policy will be discussed? What are the odds of getting it passed? In the literature, numerous varieties of political feasibility are discussed. One such theory of feasibility is the "probability of success" (May, 1986, p. 111).

As mentioned above, this theory of political feasibility attempts to judge the likelihood that one policy, given certain alternatives within the policy, be approved and implemented in a given amount of time. Obviously, these judgment calls can happen during several phases of the policy process. There will be ongoing attempts to assess the feasibility. If the odds of approval appear relatively low, the policy can be revised in order to increase its chances. Once, after the likelihood of passing seems viable, policy makers then need to decide if it is the correct time to push such a policy. This is the policy window mentioned in Chapter One by Kingdon (1984; 2003).

Another theory of political feasibility, "identification of constraints and opportunities" (May, 1986, p. 112), does just that. According to Charles Schultze, the policy maker begins to "develop a sense of what [political] constraints to recognize and

of when and how far to stretch those constraints..." (as cited in May, 1986, p. 112). As this theory sets out to prove, simply identifying the probability of success is inadequate. The probability of success can be manipulated by the policy makers, the lobbyists, and any party that is using a political strategy to pass their policy. Therefore, devising a political strategy and gauging the likelihood of success is vital in order to enact a policy.

In doing this, developing a strategy and judging probabilities, one must need to understand the support and opposition the proposed policy is facing. With this knowledge, the policy makers can then modify the proposal to increase the likelihood of implementation. Peter May alleged that "one hallmark of successful policy makers is knowing what features to include in policy proposals in order to build supportive coalitions or to reduce resistance" (May, 1986, p. 112).

A third theory, dubbed "political prices, opportunity costs, and consequences" (May, 1986, p. 113), relates more to the political officials more than the policy makers. Ralph K. Huitt thought of this as the "political price to be paid for a course of action" (as cited in May, 1986, p. 113). Any proposal or policy contains with it some political costs. A political cost, or political price, can be viewed as the "advocate's diminished store of political capitol" (May, 1986, p. 113). This could be a policy concession needed in order to get approval. Along with a political price, opportunity costs are present. An opportunity cost could be giving, or not giving a particular proposal attention. Should this policy be wait-listed for another time, or should it be enacted now, foregoing other, maybe more profitable policies? Considering these two costs, political consequences must be considered. There is a potential consequence of being associated with the implementation of a certain policy or being associated for *not* implementing a policy.

The acceptance or refusal (feasibility) of certain policies depends on whether the political actor chooses to bear the political costs and consequences. Heineman and Hessler (1980) contend that "every policy proposal must be judged not only on its merits but also in terms of its implication for the politics of governing [...], the politics of nomination and the politics of election..." (as cited in May, 1986, p. 114).

As noted earlier, the "policy window" refers to the timing of political salience in regards to the implementation of policy (May, 1986, p. 117; Kingdon, 1984; 2003). This describes the "right" time for particular proposals to be introduced, the "right" opportunity. The term also suggests a limited duration of time. Once again, Kingdon (1984; 2003), in reference to his policy streams, suggested that policies must have a policy window in order to have a chance for success. The topic must be politically salient and the attitude of the political class must be accepting of the proposed policy.

Multiple Streams

The processes, as well as the actors, can either become a motivation or a constraint in regards to successfully passing a policy proposal. Certain actors such as congressional committee chairs or the president himself can push a certain proposal through the governmental agenda. Contrarily, if certain political costs are too high (as discussed in the Political Feasibility section above), ordinarily noteworthy items could be prevented from rising on the agenda. Thus, the problem stream "can push some items higher on the agenda, but it can also retard the upward movement of others [...]" (Kingdon, 2003, p. 88).

The Problem Stream

Problems can capture the attention of important governmental decision makers in a number of ways. Sometimes, the recognition of a problem is due to some sort of indicator. An indicator can be the rising rates of certain events such as highway deaths, diseases, consumer prices, federal expenditures and budgetary impacts. On the other hand, a problem can come to the attention of political actors by a dramatic or focusing event such as a natural disaster, epidemic, or even a personal experience. Feedback is also effectual at claiming the attention of those on the Hill. Politicians are very interested in their constituent's opinions, especially if re-election is approaching. All of these occurrences affect where this particular problem will rest on the agenda.

Problems, in the eyes of government, are not conditions or situations; they are not something of a temporary nature. In order to gain the appropriate attention of the government, problems need to be defined and categorized to affect certain perceptions and interpretations in order to enact proper change. However, with the definition and categorization of problems comes great political stakes. The public, as well as political actors, will see a problem differently depending on the category in which it has been placed. One "may not be able to judge a problem by its category, but its category structures people's perceptions of the problem in many important respects" (Kingdon, 2003, p. 111). This was demonstrated in the disability rights movement. The very definition of handicapped has changed dramatically over the years in the federal codes and policies.

An example for categorization purposes is the transit problem for those who were physically disabled. Allowing physically handicapped individuals the right to ride a bus

or subway was not the same as allowing that individual access to the transportation mechanism. The argument revolved around whether or not to retrofit public transportation machines with the ability to accommodate disabled patrons or have separate, subsidized transportation options. If the problem was defined as a civil rights issue, then equal access to transportation was needed because separate was not equal. If it was just a transportation issue, then equal access was not important and other alternatives could be found. The category made an incredible difference among people's perception of the problem.

The government's first instinct is to stay the same as long as possible when confronted with the need for changing categories. A change in a problem's category or definition "represents a threat to somebody's interests [...]" (Kingdon, 2003, p. 112). However, in some circumstances, recognizing a problem can be beneficial to the elected official. Some politicians want to find a place to cast their mark or bureaucrats propose change in order to expand their jurisdiction. Activists also invest time and attention to bring problems to the forefront of the governmental agenda. They emphasize indicators by way of press releases, testimony, speeches, pamphlets, rallies, etc. They also try to bring certain problems into the personal experiences of critical key players. Many things can affect perceived problems—indicators, focusing events, feedback—all of which bring problems to new light.

The Policy Stream

Policy communities are a group comprised of specialists in a certain policy area. These can be "researchers, congressional staffers, people in planning and evaluation offices and in budget offices, academics, [and] interest group analysts" (Kingdon, 2003,

p. 116). This community of specialists, as posited by Kingdon, is self-sustaining and is unaffected by political activities such as changes of administration and pressure from legislative constituencies. This simply means that when elections occur and the administration or congress personnel change, these specialists remain. They are not tied to a particular official's office so they are never in danger of term limits or running for re-election. They are, however, affected by political events. This stream and the political stream run independent of each other and each has its own purpose.

Kingdon refers to a "policy primeval soup" in which ideas float around awaiting their opportunity to be proposed. The advocates or policy entrepreneurs do not allow all of the policies to be completely free floating. They take their pet projects and try to "soften up" policy communities as well as other public entities in order to get them used to and accepting of these new policy ideas. Then when a policy window (discussed in The Policy Window section below) becomes open and available, the policy road has already been paved and the important actors have already been exposed to this idea. Softening up is necessary in order for a particular policy to seem feasible or taken seriously.

While ideas and policies are floating around in the primeval soup, specialists must think in advance what could happen to their proposal should it be suddenly advanced into the larger political arena. These specialists must consider their project's viability for survival. Some criteria for survival are "technical feasibility, value acceptability within the policy community, tolerable cost, anticipated public acquiescence, and a reasonable chance for receptivity among elected decision makers" (Kingdon, 2003, p. 131). If a proposal fails to meet these criteria, the chance of it being considered as serious and

viable is extremely slim. If a proposal only fails one or two of these categories, then it may be reworked or perhaps combined with something else and then reenter the primeval soup. In the long run, "decision makers need to be convinced that the budgetary cost of the program is acceptable, that there is a reasonable chance that politicians will approve, and that the public in its various facets—both mass and activist—will acquiesce" (Kingdon, 2003, p. 138).

To sum up so far, policy communities produce a small number of ideas. Some are formulated and enter the primeval soup, survive softening up, and for the most part satisfy the criteria for survival. There may not be a single proposal that satisfies all policy specialists but there are a few alternatives that have risen to the top of the soup. These have then been reworked and sharpened, constraints have been identified, they have influenced people and pushed them into thinking along particular lines, the list of alternatives is narrowed and finally, a few ideas have emerged as leading policy proposals. Alternatives are an important part of the policy stream because before a certain "subject can attain a solid position on a decision agenda, a viable alternative is available for decision makers to consider" (Kingdon, 2003, p. 142). The probability of a problem rising on the decision agenda is dramatically increased if there is already a policy solution in accompaniment. The decision agenda differs from the governmental agenda in that the governmental agenda is the list of subjects or problems that are currently getting attention. The decision agenda is the list of subjects or problems within the governmental agenda that are available for an active decision.

The Political Stream

This independent stream consists of things such as the "[national] mood, pressure group campaigns, election results, partisan or ideological distributions in Congress, and changes of administration" (Kingdon, 2003, p. 145). The first component of this stream, the national mood, is the notion that a large percentage of the population nationwide are thinking along common lines, that the mood changes from time to time in discernable ways, and that these changes affect policy agendas and outcomes. The national mood can promote certain agenda items due to the notion of "fertile ground" (Kingdon, 2003, p. 147).

Fertile ground refers to a receptivity to certain agenda topics. If the governmental participants perceive a fertile ground or particular receptivity towards a certain subject, they can push that subject higher on the decision agenda. However, the national mood can also constrain certain topics from getting advancement. Since there is more than one problem on the governmental agenda at any given time, sometimes a highly viable proposal is obscured by another topic that happens to be at the forefront of attention. An example of a topic at center attention would be national defense and counter terrorism in the aftermath of 9/11. There were many proposals on the agenda dealing with health care, social security, education, and so on, but the only proposals that were going to be at the top of the agenda and therefore considered were relevant to the national mood of anti-terrorism and defense.

Government officials may sense the national mood in one of two ways. Elected officials may judge their constituents' mood by way of mail, town meetings, local newspaper coverage, and through interaction with groups of people coming directly to

their office in their respective districts. Second, non-elected officials may judge public opinion by listening to elected officials. Since elected officials are supposed to know what is going on, non-elected officials take their cue from the politicians without much substantiation (Kingdon, 1984; 2003).

Another component of the political stream is in the arena of organized political forces such as interest groups. The politicians must calculate the consensus or conflict among organized interests. These interests influence policy makers not only by what they have to say, but also by how intensely they argue their side. Politicians perceive communication as an index for intensity. If a politician hears a lot of pressure from one side and not the other, they assume the balance favors the first. However, if both sides have relatively equal communication, a politician could still favor one side due to perceived "superior political resources, such as group cohesion, their advantage in electoral mobilization, and the ability to affect the economy" (Kingdon, 2003, p. 151). As one legislative director put it:

> "[In the autism community,] there's so many different groups [...] but they're all separate and kind of working in their own vacuums and few of them talk every so often but in terms of events happening, there isn't a whole lot of communication. There is going to be some more coordination necessary to really launch a huge campaign."

This portrays a very real problem in the autism community; there is no single group consensus, the group is fractured without any cohesive set of stated goals. It is a major collective action problem. Without a cohesive community direction, it has resulted in a

lack of universal programs and policies concerning this population. This will be discussed in subsequent chapters.

Another example of organized interests is the expected building of support in favor of an existing program. The clientele the program benefits organize into an impressive collection of interest groups whose main goal is to protect that program. With this collection of clientele, it not only insulates the program from attacks, but it also makes proposed changes to the program extremely difficult. To counteract this influence, the other side that favors change organizes and cites where the current program has failed.

Next, the third key factor in the political stream comes from the government itself. When there is turnover of important officials, the agenda will change. This can happen in one of two ways. Either incumbents in crucial positions change their priorities or new personnel bring in different priorities. Administration changes bring about a new outlook on the policy agenda. Turnover in Congress gives way to committee chairs and positions and allows some topics to be brought forward and others possibly buried.

In addition to personnel change, the second aspect of government influence on the political stream is jurisdiction. Constitutions, charters, statutes and alike are used to establish jurisdictions. With the federal government, "administrative agencies and congressional committees have their claims to turf" (Kingdon, 2003, p. 155). Positions are affected by jurisdiction; agenda setting is influenced by 'turf' and some otherwise important subjects are ignored because they get caught in the drawing of jurisdictional boundaries (Kingdon, 2003, p. 2005). Turf wars usually end up hindering governmental action.

Jurisdiction can also have a positive effect by pitting two sides against each other for claim and credit to that particular jurisdiction. If the officials see political potential for an action on a certain issue, some kind of publicity or "electoral mileage", the chance of that particular issue advancing on the agenda is greatly increased. However, competition can also drive the issue's probability of success down if there is no perceived benefit or pay out for those officials vying over jurisdictional credit.

Consensus building in the political stream is similar to that in the policy stream. In the political stream, consensus among advocates and officials is more about bargaining than persuading. If there is consensus in the policy stream, if it passes the criteria for survival, then it becomes a front-runner in the policy community. In the political stream, consensus is being built by way of granting favors. One politician or advocate proposing issue B will help another official get issue A through if s/he will not impede issue B.

Along with consensus building comes bandwagons. If the perceived issue is becoming a popular hot button with the public, politicians will climb aboard to help grab some recognition and popularity. As Kingdon put it, "once an issue seems to be moving, everybody with an interest in the subject leaps in, out of fear that they will be left out" (p. 162). Consensus building and the bandwagon all contribute to potentially sharp agenda shifts. This is due to some perceived political benefit and the notion of movement in the policy world.

The Policy Window

A policy window is an opportunity for advocates, lobbyists, officials, and entrepreneurs to push their proposals through the agenda. A policy entrepreneur is an advocate for a proposal or idea that, much like a business entrepreneur, is willing to

invest their resources—time, energy, reputation, possible money—in hope for a equitable return. They can be found in or out of government, in interest groups or research organizations (Kingdon, 2003, p. 122).

A policy window is relatively unpredictable and can open unexpectedly. If policy entrepreneurs and advocates have adequately prepared by floating their idea through the primeval soup and softened up the community, this window of opportunity will not leave them behind.

This is where the three streams join together. Kingdon succinctly summarizes the process by stating that "a problem is recognized, a solution is developed and available in the policy community, a political change makes it the right time for policy change, and potential constraints are not severe" (Kingdon, 2003, p. 165). A policy window allows the independent streams to work together and produce a viable policy proposal.

Policy windows open for a variety of reasons. First, a window may open due to a change in the political stream such as an administration change, or a shift in the national mood. Next, the window may open because a hot button issue has made it to the main stream; there is a new problem that captures the attention of the officials (focusing event). A window might open if a congressional committee receives a new chair, if there is an influx of new members to a regulatory body, or even a massive shift in congressional membership.

Unfortunately, policy windows do not stay open for very long. It can close, again, for a variety of reasons. Governmental officials may feel that they have adequately addressed the problem through a type of action. The window can close if officials fail to take action altogether. This would happen if the participants are not interested or are

unwilling to take action at the appropriate time. In addition, the focusing event that opened a window could pass from the attention of appropriate actors. If an administration change opened the window, the 'honeymoon period' is over rather quickly and the decisions made thereafter will affect the agenda and close out particular proposals. Additionally, if a window opened because of a change in personnel, the personnel could change once again. Finally, the window could close because there was no viable alternative available. If there was no softening up or alternatives all ready floating around in the policy soup, then the opportunity will pass with no action. If the window passes without any action, it may be a while before that opportunity will present itself again.

In summation, policy windows can open due to specific events in the political stream as well as attention grabbing problems. Therefore, windows can be categorized as "political windows" and "problem windows" (Kingdon, 1984; 2003). The governmental agenda is heavily influenced by the political or problem windows, and consequently the political and problem streams, while the solutions or alternatives has been generated by the policy stream. Hence, the two best situations that would allow policy entrepreneurs to get their pet project on the decision agenda would first be a problem in which they may attach their solution to (problem window); or a change in administration or other political event (political window) that promotes receptivity to their specific proposal. A problem will have dramatically increased odds of rising on the decision agenda if all three major elements—problem identification, available and sufficient alternative, and political receptivity—are properly coupled together in a single neat package (Kingdon, 1984; 2003).

Conclusion

My argument expands upon the existing literature by way of the multiple streams theoretical framework. I use this framework to bring structure to a very widespread, fragmented, and debated topic. The variety of literature in this research is only an example of the numerous and disparate interests within the disability community. The current literature addresses so many subjects; however, I could only focus on a few for this particular research. The literature compiled in this thesis addressed the various needs of individuals with developmental disabilities, models for service delivery, effectiveness of programs, types of model theories, and the process of policy change.

My task is to utilize many aspects of the literature into one synthesized model that is relevant to the present environment and will help bring about change. Much of the literature expounds that the disability community needs this or that with a recommendation here or there. It is my opinion that no single article has taken into account all of these aspects and framed it in an empirical, feasible, structured argument. Utilizing the case studies and expert interviews, I have taken into account the needs of the population and service delivery effectiveness as identified by the financial statements along with the interviews. I have used the knowledge gained by the research on the various disability models as well as policy change to help recommend future, realistic policy improvements. Finally, I have synthesized all this information into an empirical framework qualified to address this topic.

I argue that my research will contribute to the existing literature by assembling numerous studies and subjects that have previously been single article topics, integrate them into an empirical framework, and apply that framework to the current national

setting. All this is in order to produce realistic policy improvements that can be embraced by any section of the disability community across the nation.

As for expectations, I expect to find inadequate funds for necessary service delivery. Regarding the organizations and case studies, I expect that there is a severe gap between what the organizations can do and what they need to do in order to successfully manage the growing number of clients. I expect with the interviews that the administrators are not completely pleased with the way their organization may be improperly funded by the government but that they are determined to do whatever possible for their clients. I also expect the foundation administrators to be slightly cynical when addressing the issue of government help and the policies currently implemented.

CHAPTER THREE

POLICY REVIEW

Many anti-discriminatory policies have been passed at the national and state level, in order to lessen the gap between abled and disabled. Throughout this chapter, I will briefly define and describe the effects of various landmark policies. These policies vary on topics from the architectural design of a building in order to accommodate those with physical disabilities to educational rights for special needs children. The timeline of these examples illustrate the evolution of disability policy from cursory changes to all encompassing mandates.

Legislation for those with disabilities can be broken down into roughly three categories: programs and services, income maintenance, and civil rights. (West, 2000, p. 15). It has been said that the core concept for any disability legislation should be grounded in full participation and independence for the individual. (Dowrick & Keys, 2001; Kennedy, 2001; Scotch & Shriner, 1997; Wells, Sandefur, & Hogan, 2003; West, 2000). The history of disability policy can be analyzed and viewed as having exponentially improved the independence and participation of disabled citizens in the broader community.

Paving the Way: Legislation That

Led up to the IDEA and ADA

One of the first policies to benefit disabled individuals was the Developmental

Disabilities Assistance and Bill of Rights Act. This legislation was integral to advancing

civil rights for those with disabilities. Originally authorized in 1963, this act focused

primarily on the establishment of University Affiliated Facilities (UAFS). These facilities

were charged with expanding the number of professionals to address the needs of persons

with developmental disabilities. (Silverstein, n.d.).

The Architectural Barriers Act, hereafter ABA, of 1968 (42 U.S.C. 4151-57)

stipulated that all federally funded buildings to be built after 1968 must be accessible by

those with physical disabilities. Examples of such buildings include post-offices, social

security offices, schools, and prisons. Accessibility requirements meant ramps for those

in wheelchairs, wider doorways, designated parking, and other specifications for

elevators, fire alarms, restrooms, drinking fountains, signs, etc. This act was significant in

that it was the first act of Congress to explicitly make physical structures accessible to

disabled citizens (United States Access Board, n.d.).

In order to enforce such standards and specifications, the ABA established the

Access Board, which is an independent federal agency. The agency was charged with

supervising and maintaining all the accessibility specifications created by the ABA. Over

time, the jurisdiction held by the Access Board to supervise federal buildings expanded to

the private sector. This agency continued to supervise building accessibility

modifications, but now has design criteria for "transportation vehicles,

telecommunications, and electronic and information technology " (United States Access

Board, n.d.). The Access Board maintains numerous and diverse records for variations of design criteria, however, it is still only charged with enforcing those design specifications for buildings.

In 1970, the reauthorization of the Developmental Disabilities Assistance and Bill of Rights Act established funding for Developmental Disabilities Councils in each state in order to coordinate and integrate the provision of services for those with developmental disabilities in the least restrictive environment. Later, in 1973, as part of the Rehabilitation Act, sections 501, 503, 504, and 508 were enacted. Section 504 has been credited as paving the way for many anti-discriminatory policies and legislation to come. This section expressly prohibited the exclusion of any qualified individual with a disability from any program or activity receiving federal funds (29 U.S.C. 794). Section 504 will be subject to controversy and embark on many changes that will be discussed in later sections. Sections 501 and 503 focused more on affirmative action plans for the hiring and advancement of individuals with disabilities within the federal government (West, 2000, p. 17). Section 508 "established requirements for electronic and information technology developed, maintained, procured, or used by the federal government" (U.S. Department of Justice, 2005).

Then in 1975, Congress created and authorized funding for Protection and Advocacy Systems in each state to ensure that individuals with developmental disabilities were safe and treated fairly. (Silverstein, n.d.). The 1975 reauthorization also established funding for projects to address national needs for individuals with developmental disabilities.

Also in 1975, the Education for All Handicapped Children Act was established. This act was later revised and is now called the Individuals with Disabilities Education Act (IDEA). This law stipulates "a free appropriate public education (FAPE) to all children with disabilities" (P.L. 94-142; 20 U.S.C. §1400 et seq.). It mandates that these special needs children be educated in the "least restrictive environment" (20 U.S.C. §1412) or "mainstreamed" into classrooms that are predominantly normally functioning.

The least restrictive environment (LRE) principle is intended to allow special needs children to learn and interact in the least restrictive educational setting appropriate for their level of disability. It is the right of the student to have every educational opportunity available, similar to their normal functioning peers. However, if a student's disability prevents them from participating in a normal functioning classroom, then s/he will receive a more restrictive setting.

The ninth circuit court case of *Sacramento City Unified School District, Board of Education v. Rachel H.* (14 F.3d 1398 9th Cir. 1994) determined four factors that must be taken into consideration while determining placement of a special needs child. The first factor is the education benefits of integrated settings versus segregated settings. Second is the nonacademic benefits, which primarily means social interaction with non-disabled peers. The next factor to be considered is the effect the student with a disability can have on the teacher and his or her peers. Lastly, the cost of supplementary services that will be required for that student to stay in the integrated setting must be determined.

In theory, the LPE principle should provide for the fair treatment and equalization, as much as possible, of disabled children in terms of education. However, in reality, the court ruling is interpreted as protecting the education of fully functioning

children. Four factors must be considered and accepted as not having a negative impact on the abled children, not for the benefit of the disabled children. It is, however, a step in the right direction.

The 1980s also proved to be a decade rich in disability policy. In 1980, the Civil Rights of Institutionalized Persons Act (42 U.S.C. § 1997 et seq.) was passed by the Congress. This legislation granted the Attorney General and the U.S. Department of Justice the power to sue individual states for violations of the rights of institutionalized persons. According to the law, institutions meant a facility such as a "jail, prison, or other correctional facilities" as well as facilities for people who are "mentally ill, disabled, or retarded, or chronically ill or handicapped" (42 U.S.C. § 1997 et seq.). It was a measure meant to protect the disabled from being violated while under governmental care.

In 1984, the Voting Accessibility for the Elderly and Handicapped Act (42 U.S.C 1973) was passed. This piece of legislation required polling places to be accessible to people with physical disabilities. This act also mandated that if there was no accessible location, "a political subdivision must provide an alternate means of casting a ballot on the day of the election" (U.S. Department of Justice, 2005). This law also required that states must make available "registration and voting aids for disabled and elderly voters, including information by telecommunications devices for the deaf (TDDs) which are also known as teletypewriters (TTYs)" (U.S. Department of Justice, 2005). Following in 1986, the Air Carriers Access Act (49 U.S.C. 41705; P.L. 99-435) "prohibited discrimination in air transportation by domestic and foreign air carriers against qualified individuals with physical or mental impairments" (U.S. Department of Justice, 2005; 49 U.S.C. 41705). The Department of Transportation was charged with enforcing this law.

Although housing was originally included in the first version of the Americans with Disability Act, it was later abandoned when the Fair Housing Act Amendments of 1988 materialized (West, 2000, p. 18). The Fair Housing Act (42 U.S.C § 3601 et seq.) prohibited housing discriminations based on "race, color, religion, sex, disability, familial status, and national origin. Its coverage includes private housing, housing that receives federal financial assistance, and state and local government housing" (U.S. Department of Justice, 2005). This was the first time that any antidiscrimination law for those with disabilities was extended into the private sector. The Fair Housing Act was a vital contributor to the goals and purpose of the Americans with Disabilities Act (ADA) (West, 2005).

Section 504

In 1988, section 504 was amended by the Civil Rights Restoration Act. This act stipulated that recipients of federal funds must comply with civil rights laws in all areas, not just in particular programs that received federal funding. (P.L. 100-259). Section 504 overturned the Supreme Court case *Grove City College v. Bell* (465 U.S. 555 1984). In doing so, those covered and defined in section 504 were broadened to include an entire entity, such as a university, instead of narrowing the scope to a particular department. The statute mandated that if a particular part or department of an entity is funded by the federal government, the entire entity must comply with civil rights legislation, not just the specific department (P.L. 100-259).

As mentioned in the literature review and above, this section had come into controversy (McCluskey, 1988). It was the vagueness of the section that disturbed most advocates. The hotly debated section 504 stated that no qualified individual with a

disability in the United States shall be excluded from, denied the benefits of, or be subjected to discrimination under any program receiving federal funding (29 U.S.C. 794). Jones (1991) broke down section 504 into the various definitions for disabilities and programs but acknowledged that in no paragraph did the section describe reasonable accommodation. In addition to the vagueness and incompleteness of section 504, the absence of any definition of reasonable accommodation was a major problem. Due to the vigorous battles the disability movement has won, many federal agencies supplying funds to other entities now require reasonable accommodations for employees with disabilities in order for such entities to receive said funds (U.S. Department of Justice, 2005).

Reasonable accommodations are those accommodations employers are required to make in order to level the "playing field" for those individuals with disabilities. Such accommodations can include but are not limited to: part-time or modified work schedules, modifying existing or acquisitioning new handicap accessible equipment, adjusting training processes/tests/policies, providing reading assistance or trained interpreters, etc. (U.S. Equal Employment Opportunity Commission, 2002). The accommodation is reasonable if it appears feasible or plausible. Restructuring the entire business plan in order to accommodate one disabled employee is not reasonable, but the acquisition of hearing impaired telephones or allowing a physically disabled cashier to sit on a stool behind the counter are reasonable accommodations. The accommodation must be effective in granting the needs of the individual.

Individuals with Disabilities

Education Act (IDEA)

The IDEA is a revised policy, originally the Education for All Handicapped Children Act of 1975. It has been reauthorized several times, the most recent in 2004. IDEA is considered landmark legislation due to its advancements of educational opportunities for school aged children with disabilities.

IDEA established IEPs, or individualized education programs. Each special needs student, enrolled in a public school, is required to have an IEP. This formal document reflects the individual needs and goals for the student and maps out the certain programs and methodologies needed to reach these set goals. IDEA also mandated that each IEP meeting is to be held annually and is developed by a multidisciplinary team consisting of the student's parents, the special education teacher, a recommended general education teacher, an administrator for the school, a program specialist (district administrator), and a member of support services. Parents also have the option to bring in an advocate or special person of their choice. This is all to better facilitate the individual needs of those who are disabled.

In addition to provisions for school-aged children, the reauthorization of Education of the Handicapped Act Amendments extended the responsibility of government funded public education to include services for transitioning between school and employment. The U.S. Office of Special Education Program defined transition as "an outcome-oriented process encompassing a broad array of services and experiences that lead to employment" (Will, 1984, p. 2). Then with the reauthorization of IDEA, the scope of transition extended beyond school to employment, but included other post-school

activities. As it was redefined in the IDEA, transition now meant "an outcome-oriented process, that promotes movement form school to post school activities, including postsecondary education, vocational training, integrated employment (including supported employment), continuing and adult education, adult services, independent living, or community participation" (Assistance to States for the Education of Children with Disabilities, 1993).

IDEA also mandated that transition services would be implemented no later than the student's sixteenth birthday. These services were a direct result from concerns of the disabled community that certain educational efforts were not being addressed. Authors Hughes and Eisenman concluded that if these efforts were not being dealt with then "we cannot expect to see improvements in the adult lives of special education students" (Hughes & Eisenman, 1996, p. 134).

In 2000, under President Clinton, IDEA was reauthorized. The Developmental Disabilities Councils in each state, which were renamed the Councils on Developmental Disabilities, were mandated to administer a federal grant program that was intended to fund services tailored for people with severe developmental disabilities. These grants were to be used for family support and a program of direct support for workers who assist those with developmental disabilities. (P.L. 106-402; Silverstein, n.d.; West, 2000).

The goals of this act were updated in order to provide individuals with disabilities with the "information, skills, opportunities and supports to live free of abuse, neglect, financial and sexual exploitation, and violations of their legal and human rights" (Silverstein, n.d.). The purpose of this act was to assure individuals with developmental disabilities and their families the knowledge of and access to "community services,

individualized supports and other forms of assistance that not only promote independence, productivity, and integration...but also self-determination" (Silverstein, n.d.).

In 2004, President George W. Bush once again reauthorized IDEA. Most of the changes that were made were specific to the IEPs. The reauthorization revised the language regarding members of the IEP team; added new provisions for making changes to the IEP, added requirements for disabled children to change school districts, added rules of construction; changed provisions regarding present levels of educational performance, benchmarks, and annual goals, assessments, and statement of services. (Job Corps Career Development Resource Center, 2006).

IDEA ensures the proper steps are taken to facilitate the education of children with disabilities. Part C of IDEA covers infants to age two while Part B covers children from age three to twenty-one. All school aged disabled children are covered under the IDEA in order to provide the best opportunity for education, no matter the severity of the disability.

Americans with Disabilities Act (ADA)

All of this policy history became integrated into the ADA. The Americans with Disabilities Act (42 U.S.C. §1210 et seq.) is the cornerstone of the disabled community. It was signed into law July 26, 1990 by President George H. W. Bush. This was an all encompassing mandate and triumph for the disabled population. It was a landmark "more for its comprehensiveness than its conceptual novelty" (West, 2000, p. 21).

ADA is divided into four sections, or titles. The first title addressed the issues

pertaining to employment. Title I mandated that entities with more than fifteen

employees must provide equal opportunity for benefits and programs available to others,

to qualified individuals with disabilities. It prohibits "discrimination in recruitment,

hiring, promotions, training, pay, social activities, and other privileges of employment"

(U.S. Department of Justice, 2005). Title I also required that "employers make reasonable

accommodation to the known physical or mental limitations of otherwise qualified

individuals with disabilities, unless it results in undue hardship" (U.S. Department of

Justice, 2005).

Title II addressed state and local government activities. This mandated that all

state and local governments "give people with disabilities an equal opportunity to benefit

from all of their programs, services, and activities" (U.S. Department of Justice, 2005).

As mentioned before, governments must make accessible and accommodate individuals

with disabilities for federally funded services such as public education, employment,

mass transportation, social services, and voting. State and local governments must also

accommodate physical disabilities in newly constructed or remodeled existing

government buildings. They are required to make reasonable accommodations for the

disabled community.

In conjunction with state and local governments, Title II specified provisions for

public transportation. Public transportation consists of city buses, subways, and other rail

transits. Authorities cannot discriminate against people with disabilities in the provision

of their services (42 U.S.C. §1210 et seq.). An accommodation public transportation has

produced are the para-transit services. These are services that pick up those individuals

unable to participate in normal transportation services, and ferry them between their destinations.

Title III covers public accommodations. Public accommodations are private entities whose service facilities include hotels, restaurants, bars, movie theatres, stadiums, laundromats, grocery stores, etc. (42 U.S.C. §1210 et seq.). Not only must these public accommodations comply with antidiscriminatory policies regarding segregation and unequal treatment, they must follow architectural guidelines for new buildings and reasonable modifications to those already existing (42 U.S.C. §1210 et seq; U.S. Department of Justice, 2005).

The final section, Title IV, is officially named Miscellaneous Provisions. These are the provisions left over and cover an array of topics. The most prominent of which was the telecommunications relay services. It basically mandated that telephone companies must "establish interstate and intrastate telecommunications relay services (TRS) 24 hours a day, 7 days a week" (U.S. Department of Justice, 2005). This allowed those with hearing and speech impairments the ability to communicate with another party through a third party assistant. Title IV also required closed captioning of federally funded public service announcements. (U.S. Department of Justice, 2005).

The Americans with Disabilities Act accomplished two tasks, as posited by West. First, it codified numerous notions and guidelines from many of the policies discussed above. Second, it extended the antidiscrimination concept from section 504 to the private sector. The result being that the disabled community now had a plethora of opportunities available to them, much like other successful minority groups i.e. women, African Americans, etc. (West, 2000, p. 21)

Baldwin (1997) does not deny that the Americans with Disabilities Act opened

many doors. She does however qualify that the disability movement still needs to work to

improve opportunities for the disabled. Baldwin did indicate where an improvement of

the ADA was needed. One of the primary concerns of the ADA was to "improve the

employment prospects of persons with disabilities by eliminating employer

discrimination" (Baldwin, 1997, p. 38). The implicit assumption, Baldwin contended,

was that "the problems of workers with disabilities are largely due to employer prejudice

and discrimination" (Baldwin, 1997, p. 38). Removing the discrimination is not

comparable to creating accessibility.

A major theme for the opposition of mandated accommodation by employers for

disabled employees is that it is too costly, or produces and undue burden, to create special

accommodations for this minority group (Baldwin, 1997; Jolls, 2001; West, 1991). This

argument generally states that, in order to accommodate employees with disabilities, as

per ADA guidelines, the cost would greatly outweigh the benefit. This heavy cost would

then disrupt the normal functioning of the establishment or entity. This cost is usually

financial; however, it has been categorized as man-hours, acquiring new technology, loss

incurred with fewer normally functioning abled-bodied workers, etc.

Baldwin asserted that this landmark policy ignored this concept. She stated that a

flaw with the ADA consisted of its lack of responsibility by allowing employers to make

the decisions, case by case. As a result, the discrimination the ADA was enacted to

eliminate is still prevalent. She maintained that:

> By placing full responsibility for the costs of accommodations on employers and
>
> by ignoring the ... problems and costs associated with hiring workers with

disabilities, the ADA provides employers with incentives not to hire workers with disabilities, particularly those workers ... [whose] problems are greatest (Baldwin, 1997, p. 52).

The ADA, along with many other legislation, was produced out of years of struggle and toil to overcome discrimination, segregation, prejudice, and barriers to improve the quality of life for people with disabilities. It has synthesized the various models discussed in the literature review in Chapter Two into a functional policy that addressed the concerns of everyday life for millions of people. As a minority group, those with disabilities have received some federally mandated policies to better ensure equal treatment. With regard to the human variation model, the ADA has encompassed so many policies, individual attention, especially from an employer, is possible. Moreover, from the disparate impact model, the ADA has most successfully eliminated more accommodation and physical prejudices than any other measure prior.

Olmstead v. L.C.

On June 22, 1999, the Supreme Court ruled in *Olmstead v. L.C.* (98-536) that unnecessary segregation of disabled individuals in institutions may be considered discrimination, based on disability. The *Olmstead* decision interpreted Title II of the American with Disabilities Act (ADA), which stated above, guarantees equal opportunity for disabled individuals in state and federal programs and services including employment, transportation, and public accommodation. The Supreme Court held that the ADA required "states to provide community-based services rather than institutional placements for individuals with disabilities" (Center for Mental Health, 2004).

The court case started in 1995 by the Atlanta Legal Aid Society on behalf of Lois Curtis and Elaine Wilson. Curtis and Wilson were mentally retarded with some psychiatric conditions and were patients in a Georgia state psychiatric hospital. The two women had been deemed appropriate for discharge from the hospital into community programs, no efforts were made to find room for them. During the numerous court proceedings, the two women were eventually placed in the community, where they had clearly benefited.

The court case resulted in the mandate, stating that: "A public entity shall administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities" (28 C.F.R. § 35.130[d]). The Department of Justice interpreted this mandate to mean that community placement is required of institutionalized disabled persons when the particular state's own treating professionals have agreed on such a recommendation (Center for Mental Health, 2004). Georgia's argument was the ADA only prohibited discrimination between disabled and non-disabled, not within the disabled community. The court ruled that was incorrect and that Title II of ADA protected against institutionalization as segregation of disabled persons and that when mental health professionals have agreed a community based service can treat a patient better than an institution, the disabled person has the right to the best treatment (Center for Mental Health, 2004).

Since this is a federal regulation, all states must comply with the *Olmstead* decision. A structure must be in place to comply with this mandate providing for services and support in the most integrated setting. Unfortunately, many states do not have the necessary funds to accommodate their disabled population.

Administration of Developmental Disabilities

Under the U.S. Department of Health and Human Services, the Administration of

Developmental Disabilities (ADD) developed the Developmental Disabilities Assistance

and Bill of Rights Act of 2000 (P.L. 106-402). This act was ratified on October 30, 2000.

It built upon the Developmental Disabilities Assistance and Bill of Rights Act of 1963.

This newer revision was much more comprehensive and gave more attention the needs of

the disabled individuals. The purpose of this act is to improve service systems already in

place for individuals with developmental disabilities and to give incentives to states to

develop more services. As stipulated by this act, the ADD must ensure that families and

individuals with developmental disabilities receive the services and supports they need in

order to achieve a more independent lifestyle (Administration of Developmental

Disabilities, 2008).

The Development of Disabilities Act established eight different areas in which the

ADD must develop and maintain programs: Employment, Education, Child Care, Health,

Housing, Transportation, Recreation, and Quality Assurance (Administration of

Developmental Disabilities, 2008). In order to meet these requirements the ADD

developed four grant programs for states with the intention of providing disabled

individuals all the rights in which they as people are entitled. The four grant programs

provide for State Councils on Developmental Disabilities, Protection and Advocacy

Agencies, University Centers for Excellence in Developmental Disabilities, and Projects

of National Significance. These programs are designed to increase independence,

community inclusion, and the general potential of individuals with developmental

disabilities.

Combating Autism Act of 2006

The Combating Autism Act (P.L. 109-416) was signed by President George W. Bush on December 19, 2006. This progressive act, which passed the Senate unanimously, dedicated $924 million over the next five years to research and the fight against autism, along with other related disorders. In an unprecedented move, the Federal government authorized funding to combat autism by way of screening, education, early intervention, more efficient referrals for treatment and services, as well as biomedical research. This funding represents roughly a fifty percent increase in autism funding by the Department of Health and Human Services. The Act also recognizes the head of the Department of Health and Human Services as the federal representative, raising autism to cabinet level priority (AutismSpeaks, 2008)). Considering that this act has been recently approved and enacted, it has been hard to find detailed literature. Most of the information was garnered by the AutismSpeaks website, the main proponent of the bill.

State Policies

The Lanterman Act (California)

The Lanterman Developmental Disabilities Services Act, hereafter as the Laternman Act, is a vital piece of legislation in California that was enacted in 1969. According to the Frank D. Lanterman Regional Center (2008), dedicated to the assemblyman responsible for passing the Lanterman Act, the mission of this law is to provide individuals with developmental disabilities and their families any and all services and supports needed to live as independently as possible. The Lanterman Act outlines the rights of developmentally disabled individuals and their families; a description of the

function of regional centers and service providers, and what services may be relevant to the individuals and their families. The Lanterman Act also illustrates how to use an IPP or individualized program plan to attain necessary services, as well as what steps to take in case of a violation of rights (Golden Gate Regional Center [GGRC], n.d.)

In addition to guaranteeing the right to service and supports for people with developmental disabilities, the Lanterman Act also created regional centers "as the central coordinating agency in a community network" (GGRC, n.d.). The main purpose of regional centers are to ensure that the clients for whom they are responsible for, receive any and all services and supports that are needed to assist those individuals in living as independently and successfully as possible in their communities. In order to accomplish this mandate, the regional center may secure services and supports directly or they assist clients and families by referring to outside service providers such as private organizations and foundations (GGRC, n.d.).

According to the California Department of Developmental Services, the number of individuals diagnosed as autistic and served by the State of California over the age of four was roughly 7,487 individuals as of December 1996. In 2006, that number grew by 338% to total 32,809 autistic individuals. These numbers are only an estimate of the actual numbers in the state. If anything, these numbers are an undercount of the total in reality. Some children may not be receiving services under the department, may not be properly diagnosed, or may have other disabilities, landing them in other disability categories (Department of Developmental Services [DDS], 2008b, p.14)

Strategic Plan for People with

Disabilities (Nevada)

The 2001 legislative session in Nevada offered Bill 513 to address the numerous shortcomings the state experienced with regards to the service provisions for people with disabilities. Bill 513 "offered a comprehensive review of state disability services and empowered the Department of Human Resources and representatives of the Nevada disabilities community to develop a long-term plan for much needed services" ("Disability Rights," 2004). This initiative resulted in the Strategic Plan for People with Disabilities that was approved in October of 2002. The plan outlined several deficiencies and worrisome predictions as well as various solutions. With a comprehensive plan in place, along with financial backing, as provided by the legislation, Nevada hopes to improve the lives of its disabled citizens and communities. The strategic plan must also comply with the *Olmstead* decision.

Some of these worrisome deficiencies involved the lack of a comprehensive information system for people with disabilities, which resulted in scattered and/or inefficient services. Adding to this problem, there was a complete absence of an information system for state agencies, private organizations, and other service providers leading to duplicated or erroneous services. It also made for delayed service delivery. Along with these problems, insufficient funds were a major concern.

The solutions to some of these problems vary from the implementation of a service outreach program, designed to inform clients of available services across the board; to a comprehensive screening program to assess all the needs of an individual in order to efficiently provide the necessary services. Also, this strategic plan ensured

increased funds to personal assistance services, child abuse and treatment services, as well as early intervention services. The strategic plan is positive movement toward assisting disabled Nevadans (State of Nevada, 2002).

In the State of Nevada, in 1995, there were five individuals between the ages of 18-21, diagnosed with autism, receiving services under IDEA. The Clark County School District in southern Nevada reported one person with autism between the ages of 18-21 was receiving services. In 2005, the number rose from five adults (aged 18-21) with autism throughout the state of Nevada, to forty-one. Of that total, thirty-seven adults were receiving services from the Clark County School District. This information was garnered from reports generated by the State of Nevada, Office of Special Education, and various other unpublished reports. These numbers are mere estimates, undercounted if anything. Some individuals may have refused services, or categorized under other disabilities.

Mental Health, Developmental Disabilities, and Substance

Abuse Act of 1985 (North Carolina)

North Carolina implemented a state policy in 1985 that was meant explicitly for the service delivery system that was designed to benefit those individuals with mental and developmental disabilities, along with those suffering from substance abuse. The system is designed to meet the needs of those disabled individuals in the least restrictive environment possible as well as the most therapeutically appropriate setting available in order to maximize the best quality of life for the client.

This act, otherwise known as Chapter 122C of the North Carolina law code, mandates that the state and local governments of North Carolina will maintain a unified cohesive system of services in order to provide consistent and efficient care. The state

and local governments are required to always make available certain core services for disabled clients. These ensured services include screening, assessment, referral, emergency services, service coordination, consultation, prevention and education. (General Statutes, 2008).

Regional Centers

Regional centers are state run, non-profit organizations that provide as well as coordinate services and supports for disabled clients. Regional centers get their budgets from the general state funds in the state that they operate. These centers vary by state in regards to the number per state and the services they offer. With respect to the three states in my research, I will discuss the regional centers found in California, Nevada, and North Carolina.

In California, there are roughly twenty-one regional centers with approximately forty offices throughout the state. Regional centers in California help to diagnose and assess eligibility of individuals with disabilities in order to implement a plan of services. A case worker is generally assigned and a client's file will follow them for as long as they are participating in the center. Most services are free of charge with the exception of small elective programs. The case manager or service coordinator is responsible for the service development plan, a source of information and referral, as well as an advocate for service delivery (DDS, 2008c).

The regional centers operating in California generally provide services and supports that include: information and referral, assessment and diagnoses, lifelong individualized planning and service coordination, early intervention services for at risk

infants and families, counseling, community education about developmental disabilities, and advocacy for the protection of client and family legal rights, among others (DDS, 2008).

In Nevada, there are three regional centers. The Desert Regional Center in Southern Nevada; the Rural Regional Center assisting families in the rural parts of the state located in Carson City, and the Sierra Regional Center in the Reno, Northern Nevada area. The main function of these regional centers is to coordinate available services for individuals with disabilities. Again, a case worker or development specialist will develop a plan based on needs and stated goals and will assist in the acquisition of the necessary services. In addition, the regional centers offer family support programs which include respite, in-home training, and financial assistance to qualifying families. Nevada regional centers provide employment and vocational services to provide job assistance and placement along with living arrangements in order to increase independence. These regional centers are mainly funded out of the State's general fund (Nevada Department of Health and Human Services, 2008).

North Carolina is an example of a state without any regional centers for developmentally disabled citizens. Service coordination is highly decentralized and completely dependent on private firms and entities. The directory of services provides a lengthy list of private firms and simply their contact information. The North Carolina Department of Health and Human Services seems to function simply as an informational and referral entity. According to the North Carolina Department of Health and Human Services, there is a state program for children with developmental disabilities that is free and voluntary (Child Service Coordination Plan) again, that is mainly an information

sharing program. It directs families where to go for certain supports. Incidentally, regional centers were found, however, only for the hard of hearing and deaf citizens (North Carolina Department of Health and Human Services, 2008).

Regional centers serve as important government agencies. These centralized agencies help coordinate the necessary services and supports from service providers, whether public or private, in a concise manner. They are in charge of client files and are familiar with history, needs, goals, and families all of which is an integral resource when developing programs for people with disabilities. It is a suggestion on behalf of this researcher that regional centers should be adopted by every state in order to have a more centralized, cohesive resource which in turn can provide for more efficient and effective service delivery.

Conclusion

The journey of disability policy thus far has been rife with struggles. All of the policies discussed in this chapter have led to the eventual culmination of encompassing, landmark policies, which have enormously improved the lives of disabled people all around the country. They have paved the way and shown the steps to achieve the necessary rights of those individuals who cannot fight for themselves. However, having reviewed these facts, there are still obstacles left for the disabled community. The ADA, and other policies, have brought this community most of the way towards independence and self-preservation, however, there is still work to be done.

I have discovered a common idea that was only pointedly addressed once in an interview but has been laced in the background of my research. Coordination is a

severely needed component in the disabled community. Coordination is needed between state agencies such as school districts and regional centers; agencies and families, between service providers, as well autism advocates and interest groups. With the new fervor autism has garnered and the emergence of many new autism advocacy groups, the needs of this highly complex population has been spread out with niche groups and short-sighted goals. A major goal for the autism community should be coordination along with the recognized, ranked, stated goals for the entire community to work towards. With so many groups pulling attention to their single priority, not enough attention is centered on the universal goals of the community. Once this coordination and cooperation has developed, only then will this cause be able to move forward and see actual results be it more government services, funds, schools, research etc.

My research is one more commentary on where the deficits lie for this vulnerable population. Without the aforementioned policies, none of the organizations discussed in the case studies could have accomplished what they have. In the following chapter, the case studies are explored and the problems faced in the current world are illustrated, followed by recommendations to correct some of the deficiencies found in the allocation of services to the disabled.

CHAPTER FOUR

CASE STUDIES

As stated in Chapter One, I have chosen these three private foundations for a number of reasons. First, three states were identified as credible units of analysis in order to give a broad sense of how services were being offered in states of varying population and wealth. Then, these three foundations were identified in each state as prominent service organizations. Secondly, each organization is a concise model grounded in the public policies and legislation of this country. Thirdly, and most importantly, although the three organizations differ in size, location, funding, and number of services offered, they all still provide similar services and programs to clients with autism and other developmental disabilities. This is the greatest indicator that needs are universal, and not a state-by-state circumstance; therefore, allowing for general recommendations that benefit all individuals with disabilities, not just particular states or organizations.

In the sections that follow, I will describe the various services, functions, and finances for each organization. The financial records for each organization are from the most recent year available. The fact that the budgets are from different years does not affect my research since I am using the information as supplemental and as an example of expenditures and the slight variation in years do not affect the general application. The purpose of including financial statements revealing expenditures and revenues are to give insight into the measures needed to operate such an organization. I hypothesize that

examining the budgets will lend credence to the notion that insufficient resources are a main hindrance to the allocation of services and fulfillment of needs. Afterward, I will then discuss the information ascertained by the interviews of elites within the autism or legislative communities and their relevance to policy recommendations.

California: The California Autism Foundation

The CEO, John Clay, started this foundation in 1982 to create a home in the community for his autistic foster son. With $30,000 in borrowed funds, the first home, dubbed "A Better Chance" opened in 1983 in San Rafael, California. The term, "A Better Chance" (ABC) is an inspirational phrase, conveying a sense that the clients of this foundation would have a better opportunity for success, rather than those disabled individuals with no services. In this first home, six severely disabled men, who were previously deemed incapable of living in the community, were able to grow and function as a part of society, by holding employment, enjoying community activities, and living as independently as possible. It has since become a success and grown into a flourishing organization (CAF, 2008; Shafer, 2006; Reiley, 2001).

Currently, this foundation caters not only to individuals with autism but also to those with other developmental disabilities. The foundation owns and operates nine licensed residential homes serving roughly 60 clients, adults and children, in the Marin, Contra Costa, and San Francisco counties. In conjunction with these homes, the California Autism Foundation (CAF) has a complex array of services to provide the essential daily needs for approximately 300 families.

CAF emphasizes empowerment and independence through the "development of communication skills, positive programming, and respect for the individual [...]" (CAF, 2008). Their philosophy is that every individual, whether normally developed or those with disabilities, "deserves to live in a real home, have a real career path and have an equal opportunity to participate in today's economy" (CAF 2008). Their philosophy is "to use behavioral modification, express the importance of diet and exercise, maximize opportunities in community activity programs and minimize medication usage in our licensed programs" (CAF, 2008).

Services

CAF offers wide-ranging services to facilitate the various needs of its clients. Such services include A Better Chance School, Day Programs, Transportation, Work Activity Program, Supported Employment, and Supported Living, along with the Mountain Air Program. The types of services provided by CAF are a direct result of client need as stated by individualized program plans, referrals from health or behavioral professionals, as well as from family requests. Once integrated into the foundation's programs, clients will also receive updates to required services by staff recommendations or by personal requests from families, caregivers, or the clients themselves.

Many services are also "contracted out" by the state government through the regional centers. Regional centers, as mentioned in Chapter Three, are non-profit organizations that operate under contract by the State of California and receive funds through the State General Fund and Federal Medicaid (Golden Gate Regional Center, 2008). They currently operate under the State Department of Developmental Services. Regional centers then pay a per client fee for services from this organization. For a more

detailed account, see Funding/Finances section below. In what follows, I summarize the services currently offered by CAF.

I. *A Better Chance School* is a non-public K-12 school that is located in Richmond, CA, the city in which the foundation is also located. It currently serves about 50 students. Student ages range from 6-22. This sole purpose for this school is to provide those students with difficult disabilities an environment in which to thrive. The curriculum is based on functional skills, skills necessary for everyday living of developmentally disabled individuals. The curriculum includes "basic math and language arts, vocational training, culinary classes, art classes, music classes, travel training and self-help skills together with a modern behavioral intervention program" (CAF, 2008). The ultimate goal of this educational approach is to have each student reach his or her full potential.

Every student receives an individualized academic program. Each student receives their Individualized Education Program (IEP), as required by the Individuals with Disabilities Education Act, which then becomes the basis for the implementation of the student's individualized academic program. Each goal in the student's IEP is broken down into smaller, more accessible steps, and therefore allows the student to be introduced to new training only after they master the prerequisites.

Students are then "regularly assessed through alternative assessments, portfolios, written documentation, the IEP document and quarterly progress notes [by the classroom administrators]" (CAF, 2008). In keeping with the guidelines of the IDEA and ADA statutes, the students are mainstreamed into less restrictive programs as soon as they are capable. The school boasts individualized transition services to help students make a

successful transition from one program to the next. Graduating students of A Better Chance School will be able transition from school to adult life with many functional skills and community experiences that will help to ensure future success and involvement.

II. *A Better Chance Day Programs* are the next step after graduation from the school. There are two sites, located in Marin County and Richmond, CA. They are "community-based entry level vocational training and activity enrichment programs" (CAF, 2008). Again, all the programs are tailored to each client's individual needs. For those with lower cognitive capabilities, this may entail "acquiring skills in self-control, communication, self-care, cooking and shopping, etc" (CAF, 2008). Those individuals with higher functioning levels, "the focus may be on learning to operate a computer or cash register in preparation for independent employment [out in the community]" (CAF, 2008).

Some training programs may include delivering Meals on Wheels, janitorial work at a community establishment, landscaping at a national park, washing and detailing vehicles, or working at the foundation owned companies. ABC Day Programs allows numerous "opportunities for social and personal development, including the ABC Choir, classes at Contra Costa Community College, Art, Music Appreciation, hip hop dance, journal writing, gardening, and more" (CAF, 2008).

III. *A Better Chance Transportation* is a service for both the family and client. The foundation owns a small fleet of vans, which provides transportation to and from the client's home. If one lives with family members, transportation is provided to the school,

work site, field trips, and activities throughout the community and beyond. It is especially beneficial for those with behavior challenges.

IV. *Work Activity Program* provides on site paid employment opportunities for adult clients. The foundation owns and operates Custom Assembly & Packaging (CAP). It is a small business that provides "packaging, labeling, and assembly services at competitive prices" (CAF, 2008). CAP currently has roughly 75 clients employed at their facility in Richmond, at the foundation's headquarters. As one newspaper article reports, "the employees at A Better Chance Industries are so happy, it's almost sickening" (Squatriglia, 1996, p. 1A). In addition to working, "consumers participate in adult education classes, taught by credentialed teachers sponsored by the West Contra Costa Unified School District" (CAF, 2008). CAF has recently acquired the San Francisco Chocolate Company and has been working to include as many client employees as possible.

The San Francisco Chocolate Company products are sold under the brand name Windsor Confections. The foundation's hope with acquiring this for-profit company is to create career opportunities for people with developmental disabilities and to generate income to supplement state support of [their] social services" (CAF, 2008). Clients of varying cognitive skill levels can enjoy work time in this program. The clients are "supervised by people who recognize [their] abilities, understand [their] limitations, and treat [them] with respect" (Reiley, 2001, p. A28).

V. *A Better Chance Supported Employment* is a service designed to support disabled adults with finding and keeping employment outside of the foundation. This service includes job training, by a job coach, and ongoing support to clients and acts as a liaison

between the employer and the CAF employee. The program provides individualized planning, "meaningful job matches, full inclusion, and creative strategies that broaden employment opportunities [...]" (CAF, 2008). CAF has developed a four-step process for effective job placement.

Step one is *assessment*. The staff carefully analyzes each client to better assess his or her special needs, cognitive level, ambitions, talents, and other interests. The second step is *job development*. This step involves reaching out to local employers in order to match particular clients with applicable employment opportunities, which are specially tailored to his or her specific skills and interests. The third step is *pre-vocation*. The coaches prepare clients for interviews as well as accompanying them through the entire hiring process. This is to ensure that the employer and employee have a reasonable understanding of expectations. The final step is *job coaching*. The job coaches on staff personally meets with each employed client on an ongoing basis to continue help them with various aspects of their employment. The coach addresses such topics as job specific training, employer and employee relationships, but also to provide personal support to the new employee.

VI. *A Better Chance Supported Living Services* is essential to independent adults with disabilities. This service provides the most independence possible by allowing a client to live in his or her own house or apartment with minimal assistance. The supported living services provides caretakers to come to the home of a client and help out with daily living activities in which the client may have trouble. These activities could involve cooking, cleaning, laundry, hygiene, or safety. The goal is to provide

mainstreamed living to those individuals whom are capable. Moreover, for those not able to live as independently, CAF also has residential care.

V. *A Better Chance Residential Care* involves living situations with more assistance. CAF owns and operates nine licensed homes for clients age 6-60. There two homes located in Marin County, six homes in Contra Costa County, and one home in San Francisco. The residents of these homes show a wide array of developmental disabilities and varying levels of independence. Those who are not able to live in an apartment on their own with minimal assistance and whose families are no longer able to provide care have the option of living in a residential home with other clients and staff. It is a much healthier alternative than an institution.

Finally, the *Mountain Air Program* was created in early 2005. In order to preserve a higher quality of life for its clients, CAF acquired a home in the Tahoe/Donner area of northern California. The goal was to create a safe and spacious vacation spot for the clients and their families. The foundation organizes weekend trips for a group of clients, transportation, meals, and care provided by staff members. It is a chance for clients to have a vacation away from their environment and provides for more independence. It also serves as respite for the families of those with disabilities.

Funding/Finances

The financial statements, obtained upon inquiry, for CAF help illustrate the type of budget that is needed to run such an extensive organization. According to the Annual Budget for 2007, the Total Revenue for Operations of the foundation totaled $10,854,454. After the Direct Expenses, the Net Revenue for Operations totaled

$10,294,482. Then subtracting the Total Operating Expenses, which totaled $10,077,136, the foundation showed a small surplus of $217,346.

The biggest contributor to the revenue was the School and Day Programs, which accounted for 39.12% of the total revenue. That translated into $4,246,580. Both the Golden Gate Regional Center (GGRC) and the Regional Center of the East Bay (RCEB) contributed a rate per client per day of $70.42 for participation in the Richmond Day Programs. With a total of 76 clients in the Richmond center, the annual amount provided by the Regional Center was $1,352,337. For the Day Programs in Marin, the Regional Center Rate was $72.42 for ten clients. Total annual revenue for the Marin programs was $357, 608. Considering the school is only relevant to children and young adults with disabilities, a financial breakdown is not necessary for this research.

The next largest percentage of revenue contribution was by the residential homes at 29.96%, which translated into $3,251,893. This revenue was generated again by Regional Center Income along with each client's Supplemental Security Income (SSI). SSI is a monthly stipend for disabled, blind, or elderly (over 65) citizens that is paid by the Social Security Administration. The funds do not come from Social Security but rather the U.S. Treasury general funds (Social Security Handbook, 2004). The amount of SSI a client receives is regulated by the State. The two categories in which clients receive money is Room and Board (R&B) and Personal and Incidental (P&I). The State decides the amount, which varies by the specific needs and costs, associated with the allocation of care per client. CAF has no authority over SSI. The Annual Regional Center contribution was $2,685,381 or 82.6% of total revenue for the Homes. The contribution from SSI was $566,512 or 17.4% of the total.

The third largest contributor to total revenue was the Supported Living service. At 12.40%, the revenue, solely contributed by the Regional Center, totaled $1,346,101. Following is the Supported Employment service which generated $734,295, or 6.76% of the total revenue. The major contributor to the Supported Employment total was the CAP work program. The Department of Rehabilitation provided $34.25 rate per hour to the nine clients currently working outside of the CAP program. These clients were approved to work up to twelve hours a week.

Transportation also provided revenue of up to $803,373. Transportation generated revenue by the GGRC rate per vehicle service hour ($46.35) along with the RCEB rate per client per day ($8.91). Along with the two regional center contributions were the various school districts that needed to provide outside resources for severely disabled students.

With the numerous ways this foundation receives income, the expenses need to be addressed. Direct Expenses for the Home and Supported Living combined amount to $225,576. The School and Day Programs amount to $300,752. Rehabilitation expenses total to $3,583, and production expenses for CAP amount to $30,060. These figures combined and subtracted from the Total Revenue result in the Net Revenue for Operations. The remaining money was spent on Personnel, Occupancy Expenses, and Operating Expenses. Personnel occupied 76.98%; Occupancy Expenses which involved building rent, mortgage interest, utilities and alike totaled 6.58%; and Operating Expenses, which consisted of professional fees, insurance, office expenses (supplies, printing, postage, etc), equipment expenses, vehicle expenses, marketing, etc. totaled 7.9%. With all these expenses, CAF still managed to come out in the black for this year.

Other years, they were not as fortunate. The amount of money spent per client for the California Autism Foundation was $33,590.45. Per client expense is a result of dividing the operating expenses directly affecting clients ($10,077,136) by the total number of clients (300) in the organization. CAF spends the most per client because a large portion, 20%, of the total number of clients are completely dependent on the foundation for their daily lives. CAF houses 60 disabled adults and must provide for all the daily necessities of an individual with minimal reimbursement. The other two organizations do not have such extensive residential services like CAF.

CAF is able to match their expenses with revenue, but not by much. Serving nearly 300 clients and operating two businesses, a private school, group homes, day programs, supplemented living, etc., they are operating very close to the margin. When asked to describe ways in which CAF could improve their budget to allow for more surplus, the clinical director stated that with more funding, CAF would be able to improve staff wages or expand the CAP business, which would in turn bring in more revenue. With more funds, this organization could improve any areas they feel are lacking.

North Carolina: Easter Seals UCP

In 1907, Easter Seals founder, Edgar Allen, lost his son in a streetcar accident in Ohio. His son's death was partly attributable to a lack of adequate medical supports. Following this tragedy, Allen began a fundraising campaign to build a hospital in his hometown of Elyria. While on his crusade for his hospital, Allen discovered the horrible truth about children with disabilities in the early 20th century. He found that most

disabled children were hidden away from public view in either their home or in psychiatric institutions. This information inspired him to found the National Society of Crippled Children in 1919. This was the first organization of its kind (Easter Seals, 2008).

In the springtime of 1934, the society launched its first fundraising campaign, its Easter campaign. Donors would put a seal, emblazoned with a lily, on their donation envelopes, along with letters and papers. The lily represented "simplicity for the right to live a normal life" (Easter Seals, 2008). It was officially incorporated as the Easter Seals' logo in 1952. With overwhelming support, by 1967, the Easter "seal" was so well known, the organization officially adopted the title, Easter Seals (Easter Seals, 2008).

In 2004, Easter Seals North Carolina merged with United Cerebral Palsy of North Carolina to create this organization. Its purpose is to "create opportunities, promote individual choice and change the lives of children and adults with disabilities by maximizing their individual potential for living, learning, and working in their communities" (Easter Seal UCP, 2008). This organization boasts a clientele of more than 15,000 disabled children and adults.

Services

According to the Easter Seals UCP website, their numerous services cover: therapy, child development centers, residential living, in-home and community-based supports, supported employment, community inclusion services, day programs, respite care, and disability benefits counseling. They also provide information, referrals, and advocacy to the families of disabled individuals. Easter Seals also has contracts with the state government to provide services. According to an administrator, "we have grants,

Medicaid funding, state dollars, school system funding, fee for service. But of course, that is never enough."

I. *Individual and Community Supports* assists children and adults to function and contribute to the community. The purpose of this service is to provide individualized support and assistance to the client in obtaining his or her personal goals for living and working in their community. In total, this support serves 825 clients (Annual Report, 2005). This service can be broken down into numerous specific services with a particular target audience.

The first service for people with developmental disabilities as well as adults with age-related needs, is supported living, personal care, respite, as well as day programs. The supported living service assists the clients to develop the skills necessary to live as independently as possible at home. Such skills include training and personal assistance with daily living activities along with the necessary support to promote participation in various community activities. In conjunction with supported living, the personal care service provides the assistance needed to support an individual in daily life activities such as basic housekeeping and meal preparation. These are in-home services and may include assistance with personal grooming such as bathing, dressing, and toileting.

A vital service to both the client and his or her family is respite care. This service offers temporary relief to children and adults with disabilities, including aging adults, so that families can take a break from the daily stresses involved with caring for an individual with disabilities. Respite may be provided as an in-home service or a designated place in the community. The type of respite is determined on an

individualized basis, taking into consideration the needs of the disabled individual and the family.

Another service for adults with developmental disabilities and age related needs is the day habilitation and community based services. This program offers support to children and adults to try and evoke participation in their community. The philosophy of community participation is the hope of building "natural support systems" (Easter Seals UCP, 2008) and generate relationships within their community. This service helps to develop skills necessary to enhance this community involvement which would then help enhance the community as a whole. The more independence an individual with disabilities gains, the more beneficial his or her involvement is in the community. As one administrator stated, "fostering independence increases productivity within the community which then alleviates some burden of the state."

The next target audience under the Individual and Community Supports services is the clients needing residential support. The supports for residential living offer clients opportunities to be as independent as possible. The first service Easter Seals UCP offers is alternative family living. This program provides a home for clients currently unable to live by themselves. As with a foreign exchange student, a qualified family with enough room and capability open their homes for a disabled individual.

In addition, residential supports, consist of regulated houses and apartments where clients can live in a group home setting. Those clients who are unable to live alone but are able to live well with others have the option of living in shared quarters. These apartments or homes are regulated by this organization. Again, fostering independence is crucial in this community and therefore, by giving eligible individuals the opportunity to

gain some independence as well as assist others with similar disabilities becomes an important objective.

The final service offered under the residential supports is the Host Homes. This program provides a supportive home environment for clients that experience mental illness challenges; it is a temporary arrangement with a host family. The client is in need of short term housing while they participate in a recovery program. Currently, this program is "only available in the greater Neuse area of Carteret, Craven, Jones, and Pamlico Counties" (Easter Seals, UCP, 2008).

The additional support services for the individual and community support programs are Real Choice, Youth Leaders in Action, and the information and referral service. Real Choice is an individualized support service that allows eligible clients to have as much influence of their allocation of services as possible. This involves "planning services, creating and implementing budgets, employing staff, scheduling services, and making choices that work best for him or her" (Easter Seals UCP, 2008).

The Youth Leaders in Action work in the Winston-Salem area of North Carolina. They work to "empower middle and high school youth with developmental disabilities [...] to develop knowledge, skills, confidence, and relationships necessary to participate as leaders within their community" (Easter Seals UCP, 2008). And finally, the information and referral service is just that. It provides information about Easter Seals UCP of North Carolina and their various services and programs, as well as referrals to outside services or organizations.

II. *Child & Family Services* primarily assists families with young disabled children. The family is allowed to have an integral role in choosing and designing

necessary services that support their child, in the least restrictive way. This organization allows the child and family services to be administered in the family's home or in an outside compatible arena, such as a child development center, school or clinic. Easter Seals UCP contends that early education and intervention services for young children, and their families, are necessary for determining and providing the best possible set of services. As of 2005, 2,625 people were served by the early education and intervention service (Annual Report, 2005).

UCP provides a fairly comprehensive early education and intervention service package that is developed through a network of relevant merchants, such as child development centers or clinics. The network is disbursed across the state, to better facilitate necessary services to families that may live quite a distance away from the Easter Seals headquarters. Most services are determined by the child's eligibility for an Individual Family Service Plan (IFSP) for children up to two years old, or an Individual Education Plan (IEP) for children ages three and older. Other early childhood services like physical, speech or occupational therapy can be initiated by the family and accompanied by a physician's order.

As with disabled adults, children can participate in developmental day programs. This organization operates twelve developmental day centers throughout the state. Each center provides comprehensive childcare with highly qualified staff. If the child has an IFSP or IEP that does insist on some type of therapy, be it physical, occupational, etc., each center is equipped to provide such services. These centers are mainstreamed so the organization boasts about a 50-50 make up of typically developing and developmentally disabled children.

In addition to receiving minor therapies at the day centers, families can opt to receive children's therapy services. These services which include physical, speech, and occupational therapy are available to children up to 21 years old. Each service is personalized and is in conjunction with family participation, to better insure the child's development. These services can be provided in either the child's home or in some other eligible location such as a childcare center, school, or clinic. Children with a variety of conditions, whether it is a birth defect, injury, or are at risk for developmental delays, are able to benefit from the therapy services offered.

Comparable to the individual support service for clients with mental health issues, Easter Seals provides supports for children and families that may also be dealing with mental health issues. Mental health issues are primarily emotional disturbance and illnesses such as schizophrenia or substance abuse induced mental illness. The community mental health service program provided by Easter Seals is entitled ASAP. The services provided are designed by the families, to better estimate the set goals and probability of success. Once again, these services can be implemented in the home, clinic, school, wherever it would be most beneficial. The services of ASAP are based on three principles.

The first principle is recovery. The most basic concept of mental health issues is that the afflicted person can recover and be free of symptoms. The next principle is resiliency. The principle promotes the strengths of the individual. With the strength and willingness of the client, they will be able to reach his or her goals. The final principle is interdependency. While the biggest goal in the disabled community is independence, the

mental health services believe that the family or support structure of the individual is vital to sustained success (Easter Seals UCP, 2008).

III. *Supported Employment Training (SET)* is a crucial component to the Easter Seals UCP organization. SET administers services all throughout the state as well as South Carolina. Easter Seals UCP takes great pride in its program, helping disabled individuals find and keep jobs, to help promote independence. Currently, they support over 900 individuals working throughout the Carolinas. In the year 2006, "SET secured 292 new job placements for individuals [they] support across the state" (Easter Seals UCP, 2008). Individuals with not just high functioning cognitive capabilities or minimal impairments can benefit from SET. SET finds jobs for clients with severe developmental, cognitive or physical disabilities.

SET fosters relationships with numerous businesses and employers and like any job placement service, the staff selects an individual that matches the job offer. They work with the clients to determine career goals and capabilities. Once the client is placed in the job, SET continues to provide job training, whether at the job site or at the service center, for as long as needed to help reassure the employer the client has the necessary skills. Once the training has been completed satisfactorily, the staff at SET will conduct follow up visits the help insure job performance and the client's well-being. Follow up visits typically are a weekly to bi-weekly occurrence, however, some individuals require daily assistance, which SET satisfies.

This supported employment program is funded "first by the [North Carolina] Division of Vocational Rehabilitation (NCDVR) who has offices" (Easter Seals, UCP, 2008) throughout the state. The funds provided by NCDVR are allotted to the career goal

assessment, job searching, and then the intensive job-training phase. The follow up visits SET provides for the clients "are funded by a variety of services including county adult service funds, Medicaid funds and other local or state resources" (Easter Seals UCP, 2008). The supported employment program serves roughly 201 clients (Annual Report, 2005).

Easter Seals UCP of North Carolina also provides "durable medical equipment" to approximately 43 clients afflicted with physical disabilities. The equipment is utilized for daily living activities. This organization is able to purchase items through this program to provide the necessary tools that clients may not be able to afford on their own.

Lastly, Easter Seals UCP provides information on a wide array of disability services and resources as well as refers to other statewide entities that may offer applicable assistance to those with disabilities.

Funding/Finances

The most recent report available was the 2005 Annual Report, which was obtained through the internet. Easter Seals UCP boasted an annual income for that year of $49,500,128. However, this organization accumulated $52,417,090 in expenses. Their 2005 fiscal year ended with a deficit of $2,916,962.

First, the income report will be broken down by category. The largest piece of the income total, at 85%, was from the Program Service Fees. This amounted to $42,100,904. The programs are those referred to in the preceding section of services for UCP. The next largest portion of income for this organization came in the form of Government Grants. In 2205, $4,170,361 or 8% of Easter Seals UCP total income was

generated by grants from the federal and state governments. Following in size was

Special Events, contributing $1,535,876 or 3% of the total. Personal Contact, or personal

donations, grossed $461,932 or 1% of the annual income for this organization. The

remaining 2% was categorized as Other with no further explanation. That total came to

$1,231,055.

The expense report can be broken down into a few more categories. The largest

portion of expenses came from the Individual and Community Supports program which

equaled $13,009,752 or 25%. Next in size was the Early Education and Intervention

program, which came to $11,615,850 or 22% of the total expenditures. The Mental

Health Services totaled $8,363,412, which was 16% of the whole. At 10%, Operations

expelled $5,234,047. Closely following Operations expenditures were the Child

Placement and Group Homes expenses. They each were equally 9% of the whole,

spending $4,646,340. The Supported Employment Training (SET) took 7% of the pie,

which totaled $4,181,706. Subsequently, Development and Fundraising only consumed

$483,941 or roughly 1% of the total expenses. Finally, the smallest two categories were

the Professional Education and Public Health Education expenditures.

The amount of money spent per client for Easter Seals UCP was $3,446.50, as a

result of dividing the operating expenses directly affecting clients ($51,697,447) by the

total number of clients (15,000) in the organization. This organization caters to a

dramatically higher number of clients then CAF, which accounts for a bigger budget. It is

difficult to understand the reason for such a large net loss for the 2005 year without the

previous year's reports. In addition, the 2005 Annual Report does not give a line item

calculation for expenditures or revenue, only the block categories as described. However,

a discrepancy that large can strongly attest to the inadequate funding for this organization.

Nevada: Opportunity Village

In southern Nevada in 1954, a group of families with disabled members was looking for a way to improve the lives of their loved ones. They founded Opportunity Village in Las Vegas, a non-profit organization boasts to be "Las Vegas' Favorite Charity" (Opportunity Village, 2008). Opportunity Village caters almost exclusively to adults with disabilities, operating two work center campuses and one thrift store all in southern Nevada. It is an almost entirely self funded organization that serves more than 3,000 people through rehabilitation programs, vocational training, job placement, and social recreation programs. Opportunity Village operates with little to no government contracts or grants. It also operates a vehicle donation program. Opportunity Village trains and places hundreds of disabled adults in jobs throughout the community, and hosts some of the most popular special events in all of Las Vegas, including the annual Magical Forest.

The annual holiday fundraiser begins Thanksgiving Day and is a chance for the Las Vegas community to volunteer and support this charitable foundation. Volunteers and supporters include various valley companies and individuals including the construction and real estate fields. Groups can donate time, money, or decorations to populate the "forest." Decorations can be anything from lights, trees, and holiday characters to actual playhouses such as a "gingerbread house" or "Santa's workshop." The Magical Forest "epitomizes community spirit and volunteerism" (Devore, 2007).

Services

I. *P.R.I.D.E* is a project that directly provides for the needs of families of adults with severe mental retardation that are also medically fragile. P.R.I.D.E. also provides day services for the children who reach the age where they are no longer in the care of the Clark County School District; which can be the age of 18 to 21, depending on whether the individual declines further service from CCSD after the age of 18. In order to be eligible for this program, the primary diagnosis for the adults must be a form of mental retardation. The individuals must require some sort of medical intervention during a normal day for "feeding, breathing, or other primary life functions" (Opportunity Village, 2008). They must also require a form of assistive technology in order to communicate with the outside world. This program allows families to keep their disabled members at home with them, rather at an institution or clinic.

The goals for P.R.I.D.E are similar to the other organization's programs. They wish to enable as much independence as possible for the disabled individual. Since the individuals participating in P.R.I.D.E have much more severe disabilities than the average client does at the other organizations, their independence is limited. However, Opportunity Village still works to broaden their opportunities to participate in the community. Through all the means necessary such as assistive technology, the program works to increase communication skills to allow the individuals the ability to express their rights and desires.

With the training to use the adaptive technology, a goal is to decrease or minimize the potential for deformities. The staff works to strengthen the range of motion, proper positioning of limbs, and stimulating activities in order to increase functionality of the

individual. Adaptive technology will help to enhance communication abilities "through the use of assistive technology, augmentative communication and a sensory enriched environment" (Opportunity Village, 2008). With this adaptive equipment, physical or occupational therapists can enhance range of motion, which may allow for greater functioning. With all the movements and exercise the staff and therapists put the individuals through to increase their communication capabilities, it also works to decrease the tendency of respiratory infections. Without the exercises and activities, the individual can be stagnant which could lead to any number of infections or diseases.

II. *Project ENABLE* is a community-based program that allows individuals with "intellectual" disabilities to be productive and active in their community. It provides the services, support and supervision necessary for the clients. Intellectual disabilities are the organization's term for developmental disabilities such as autism, Down's syndrome, Fragile-X; those disabilities that do not hinder the individual physically. They are individuals with moderate to severe mental retardation. This project serves those with limited productive capabilities due to frequent behavioral outbursts and who have minimal attention spans. This project is "designed to bring out the best potential in these adults by targeting and developing their strengths" (Opportunity Village, 2008).

III. *Community Services* offers assessment and skills training so that disabled individuals can develop work skills, competence and confidence towards living independently. Work Assessments are performed in an integrated work setting meaning that the disabled individual may be working with other non-disabled employees. Eligible individuals are "referred and funded by the Bureau of Vocational Rehabilitation" and are assessed on certain qualities such as work readiness and social interactions with

supervisors and other co-workers. There are various jobs disabled individuals can participate in throughout the southern Nevada community.

The first is the Janitorial Assessment Program. This consists of cleaning offices, bathrooms, and windows vacuuming, dusting, along with trash removal. Another part of the janitorial assessment program is landscaping. Individuals perform general grounds duty including mowing lawns, pruning trees, and checking irrigation equipment.

Next is the Culinary Assessment Program. This places the individual in a restaurant setting. Their responsibilities consist of "dishwashing, bussing and setting tables, serving, kitchen sanitization, cashiering, and [even] food preparation" (Opportunity Village, 2008).

Third is the Retail Assessment Program. This takes an individual through the retail environment. The job tasks can include unloading, cleaning, tagging, and stocking the merchandise. The employee may also train to use the cash register, depending on their capabilities.

The Office Assessment Program allows the employee to experience working in an actual office setting. The individual is trained to perform various tasks such as filing, answering phones, taking messages, and perhaps light computer work. Another work program is the Warehouse Assessment Program. Clients are trained to work in the areas of shipping and receiving, inventory tracking, inventory control, stocking, and delivering merchandise.

Opportunity Village has a Career Opportunity Job Development program as well. It starts with a job development stage in which the clients receive assistance applying for jobs, getting into contact with employers, the knowledge of how to market their skills.

All of this will hopefully culminate in the acquisition of gainful employment. Along with job development assistance, this service also offers job placement services to surrounding businesses seeking to hire eligible and motivated disabled individuals. Work at this organization's two work centers is often the only option available to people with severe disabilities in southern Nevada. Being employed and earning wages not only improves their quality of life and confidence, but it allows them to become productive members of society.

IV. *Job Discovery Program* is a partnership with the Clark County School District. The purpose of this program is to provide vocational training to CCSD students who require a supported employment arrangement in order to find successful employment. Students selected for this program will have minor disabilities but still need the intensive training. The students are seniors who have accumulated enough credits to graduate with an "Option 2 diploma" (Opportunity Village, 2008). The students must be currently enrolled in the school district and must demonstrate the ability to stay on task with minimal assistance in an assigned work area. The program is a full year long course and students must agree to attend during the summer session.

The program is comprised of multiple worksites where the students are exposed to various activities. Students are given the chance to develop skills in several areas where they may have some limitations. These areas include "work-appropriate socialization; interpersonal skills; task completion; self-monitoring; specific work skills; industrial kitchen worker/ food prep; small-scale kitchen worker/ food Prep; custodial; retail; animal care; child care; and library services" (Opportunity Village, 2008). During the twelve-month course, the participants will have the opportunity to work in different areas

for nine weeks per site. The students are encouraged to sustain participation past the required twelve-month course, in order to increase the student's success in sustaining employment.

V. Other products and services offered by Opportunity Village work centers include "[...] document destruction, mailing services; packaging and assembly of various products, including food and beverage condiments; sewing of coin bags, aprons, banners, flags, and other items; producing promotional buttons and other items; poly-bagging and shrink-wrapping" (Opportunity Village, 2008).

Funding/Finances

The financial statement for Opportunity Village Foundation, Inc. covered the fiscal year ending June 30, 2007. The financial document, generated by an independent auditor was extremely confusing and difficult to interpret. With no real itemized budget laid out, I had to uncover the dollar amounts for revenue and expenditures for that given year. If done correctly, the total unrestricted revenue, gains, and support for Opportunity Village totaled to $5,829,802. The expenses for this organization came to $3,586,480. This leaves a balance of $2,243,322. This amount does not necessarily represent a surplus since expenses were described as functional expenses, not covering items associated with specific programs but rather those costs associated with running a foundation. These costs can be categorized as staff salaries, payroll taxes, employee health insurance, bank fees, utilities, insurance and taxes, transportation, advertising and publications, maintenance, etc. There was no mention of expenses specifically program related such as expenses for supported employment, Project P.R.I.D.E, Project Enable and so on.

The net assets for total unrestricted revenues were categorized into Public Support and Other Revenues. Public Support consisted solely of organization and individual contributions, which totaled $462,463. Other Revenues consisted of Fundraising revenues, which totaled $4,092,829, by far the biggest chunk of revenue generated for this foundation. Interest, Dividends, and Other showed a total of $180,236. Gain on Investments came to $604,558 while Gain on Sale of Assets only brought in $806. Finally, Net assets released from restriction due to satisfaction of program restrictions came to $488,910. The approximate amount of money spent per client for Opportunity Village was $1195.50, a result of dividing the operating expenses ($3,586,480) by the total number of clients (3000) in the organization.

The financial statement went on to describe other assets such as property value, investments, property and equipment values, and donated inventory. These were not factored into the net revenue total because the value of a vehicle or property site does not equate to current or unrestricted cash needed to actively fund programs. It is unclear where the foundation truly lies regarding cash in and cash out for programs.

The total amount of expenses and unrestricted revenue is not surprising that it is so much less than the other two foundations. This foundation does not provide group homes or services for children and therefore have a smaller budget. What this foundation specializes in is granting work experience and wages in order for their clients to be more independent and self-sustaining. It takes some burden off the state by providing job opportunities so the client's can make money to contribute to some services. They make enough to have some meaning and purpose to their day but not enough to be free of state supplements.

With a more in-depth financial statement, it would become clear where the organization actually stands in terms of deficit or surplus. However, as of 2005, Opportunity Village served roughly 550 employee-clients. These are the clients able to work and earn some wages. These do not include the clients unable to work, such as those in Project P.R.I.D.E and Project Enable. In comparison to CAF, with roughly 300 clients total, those working, those in school, those in group homes; Opportunity Village is working on roughly half the budget with nearly double the caseload. This organization, out of the three represented, is direly in need of funds. They also receive the least in government support such as grants or contract fees.

These three organizations have shown three different ways to deliver essential daily services to an array of developmentally and physically disabled citizens. Their budgets are not adequate, barely capable of covering expenses, one not capable at all. Two organizations function with a small amount of government support, one with hardly any at all. Two organizations bring in revenue mainly by privately owned companies, allowing their clients job opportunities and work skills. One brings in revenue primarily by service fees. Two cater to adults and children; one is designated solely for adults. All three reside in different states and all three absolutely essential and indispensable in the lives of the clients and their families.

Interviews

To add depth to these case studies, and to develop a more extensive understanding of the various trials and tribulations within these three organizations, personal elite interviews were conducted. Five interviews were conducted in person utilizing a digital

voice recording device, with explicit permission from the subject. One interview was conducted over the phone, as well as two interviews were conducted in person and the subjects denied the use of the digital voice recorder. Each and every subject was informed of the purpose and content of the interviews, guarantees of confidentiality, as well as given contact information in case the subjects had questions later. The length of the interviews ranged from fifteen minutes to over an hour but generally ran about half an hour. The interview questions were open-ended.

Those individuals interviewed were chosen utilizing two methods. The first, I identified prominent administrators by way of personal knowledge and staff listings on the organization's websites. Second, a snowball technique was employed by which the first subjects interviewed were asked to identify others that should be interviewed (Schutt, 2006, p. 158). This sampling technique was useful to identify prominent individuals within this certain population. In order to identify individuals with elite knowledge or experience, those already known in the community as experts were essentially asked who they believed were also experts or highly knowledgeable. The goal of these interviews was to speak to important, specifically knowledgeable, well-informed people in and around these organizations to better explain the processes and obstacles involved with addressing the needs and services of this vulnerable population. They were important because they could inform this researcher about perspectives and specialized knowledge as well as provide reasonable coverage within the disability community. This sort of selection seemed more appropriate for this type of subject than any statistical sampling procedure.

The interviews were designed to acquire a deeper understanding of how policies affect, adversely or beneficially, these organizations and what it was these administrators, advocates, legislative directors, etc. would like to see happen. I interviewed eight people in total. I interviewed two individuals within CAF as well as one advocate from California. I interviewed one legislative director and one political consultant in the Senate of California. I interviewed two administrators in Opportunity Village and one administrator at Easter Seals UCP. Since the state government has little to no contribution to Opportunity Village, it would not be effective to interview a Nevada State official as to their knowledge and participation within this community. Easter Seals representatives were extremely difficult to reach and unfortunately, only one individual was willing to participate and was unwilling to recommend any other participants.

The interviews included questions regarding the identification of specific needs of adults with autism, as well as which needs were not being addressed. Additionally, what, if any, obstacles were present in the allocation of those needs. Questions were asked regarding the effect of federal or state policies had on the organizations ability to provide services for adults with autism (or other developmental disabilities); as well as what changes these experts would want to bring about for adults with autism on a whole. With regard to the legislative director and state bureaucrat, the subjects were asked questions about the trends of policies currently being debated in the legislature, and the various pressures from interest groups, if there were any. Also, any recognizable themes in the types of services asked for by this community, and what recommendations or possible directions would s/he have for future policy. For examples of the questions asked, refer to the Appendix.

The result of these interviews came up with a single coherent theme weaving through the various and sometimes differing responses. The common theme for each interview was the notion that the most beneficial action from the federal or state governments would be the allocation of more resources, i.e. money. No matter the position the subject held, whether they were the executive director, advocate, legislative director, or head of development, each subject agreed that more money was absolutely necessary to combat substandard services. As one clinical director candidly stated, "It's all about the money." Supporting that idea, when reviewing the Funding/Finances sections above for each organization, although the budgets are in millions of dollars, these organizations are barely getting by if they are not totally in debt. With very little support from state governments, and hardly any at all from the federal level, these organizations must depend on the community around them for fundraising, donations, and volunteers.

Following closely and very directly related to money was the necessity for more properly trained staff. With more resources available, these organizations would be able to pay for training that is more extensive. In addition, with more funding, these organizations would also be able to hire better quality people. The clinical director at CAF simply acknowledged that "finding qualified staff is one of the biggest challenges" to meeting the needs of the clients. All but one subject affiliated with an organization agreed that the lack of effectively trained or qualified staff was one of the biggest obstacles their organization faced. Human and social services are well known for low wages and stressful work. As commented by several subjects, individuals with higher education and training are not likely to take a job with substandard pay with extra work.

If these organizations were able to pay competitive wages, they would be able to hire better quality staff, which would improve the quality of services and life in general for those with disabilities, which can then improve production and involvement in the community.

When asked what would benefit the autistic clients of these organizations the most, the administrators for the California Autism Foundation and Opportunity Village all agreed, "unlimited resources." As unlikely as unlimited resources for large non-profit organizations would be, that answer undoubtedly illustrates one of the biggest concerns and main problems faced by the charitable foundations. The need for money has been proven an unavoidable obstacle.

Without explicitly stating the need for money or resources, answers to similar questions varied widely between organizations, however, the theme of money and resources was still underlying. When asked what the most necessary needs of autistic adults were, some answers ranged from "clear and concise treatment and education programs, [...] physical space"(OV administrator) to "independent living skills" (CAF clinical director) to "respite care and recreation services" (advocate). Although these answers seem very different, the common element is that all of these suggestions revolve around the need for more resources.

However, the subjects were questioned on opinions of current active policies and responses did not make its way back to money. When asked if federal policies like ADA, IDEA, or alike benefited these organizations at all, the answers were positive however revealed that ADA did not directly effect the organizations but benefited the disabled community nationwide. The executive director of Opportunity Village responded, "the

Americans with Disabilities Act has made giant strides for the disability community as a whole" but has no real effect, beneficial or otherwise, on the organization. The directors from CAF and Easter Seals responded in a similar fashion. The administrator from Easter Seals stated, "I cannot really imagine where we'd be without ADA."

Responses to questions of recommendations for future policies or directions the government should take were not as similar. Both the legislative director and political consultant proposed more adult autism legislation. The legislative director recommended topics autism advocates interested in changing legislation should focus on such as:

Address[ing] the issues of housing and employment that they have right now, and I think that there is also just a need for more education policy. There is a need for a public information campaign, which can be done through the various state and federal departments that deal with the autistic population.

These would be departments such as the U.S. Department of Health and Human Services, Office of Special Education, Department of Disability Services, etc. An executive director of one of the organizations had a more specific recommendation. His recommendation was for the federal government to remove the limit on a disabled person's SSI, bringing the interview back to funds.

When a disabled individual receives SSI, they must not amass more than $2000 at one time or the services will be terminated (Social Security Administration, 2008). There is no allowance for savings. This is unlike services for the blind where they never lose all of their services no matter the amount of money they make. As stated by executive director, those individuals that are blind are "then encouraged to work because no matter

how much money they make, they only gradually lose benefits over time but never hit a cliff where all the benefits are just gone" as with other disabled individuals.

This seems to put an unnecessary burden on the government. If the limit were to be removed, disabled individuals would be encouraged to work more and amass some savings, while still receiving some supplemental income, which would then allow them to pay for some services instead of being completely dependent on the state. The income restrictions only allow for two scenarios: either use all of the SSI and work only enough to not disrupt the services benefit, if at all, or work more but have no benefits of SSI, which then puts more pressure on other entities for care. If an individual makes more than allowed by SSI, but not enough to support him or herself independently, the individual will need to search for services in entities such as homeless shelters, free clinics, possibly institutions due to the inability of self-preservation. They would end up being more of a burden on the state then if the government would allow some supplemental income along with the wages earned by the individual.

Additional recommendations for the future included "a more concerted effort towards developmental disabilities as a whole" by both state and federal governments (political consultant). The administrator at Easter Seals contended that "they need to pour more money into Medicare because it's going to go broke," referring once again to the government. A more cynical perspective offered by an administrator at Opportunity Village, "look to private donors, the government doesn't want to spend the money." Although these recommendations differ from each other, these statements reiterate the lack of support felt by these organizations. The majority of responses from the elite interviews circled around their common theme: resources.

The interviews helped to uncover the opinions of those directly responsible for providing services to adults with autism and other disabilities. The people in 'the know' all agree that more money and resources need to be directed toward these services, be it private or public service providers. The budgets of these extensive organizations provide evidence of the lack of government involvement and the necessity for more funds. Policies must now be recommended in order to try to alleviate the gap between how services are now and how services could be in the future.

CHAPTER FIVE

CONCLUSION

The literature review denoted more research and more comprehensive services were needed. The policy review provided a background of what was available on the federal level. The case studies provided an intimate view into three organizations, representing three states, and the various means to deliver services. The interviews provided elite knowledge about the obstacles involved in providing effective services, identification of serious deficiencies in allocation of needs, along with recommendations for preferred directions. John Kingdon's Multiple Streams framework allowed the data to be synthesized into clear policy recommendations.

Are the current policies in place effective in bringing adequate services to autistic adults? It is the position of this thesis that current services and provisions are not adequate. Some needs are being met, but in a substandard way. Service providers are available to clients that can afford services; however, these providers do not have adequate funding. Services and programs lack trained or qualified staff, space for the amount of clients in need of services, and resources to provide for needs successfully. Policy must be improved in order for the needs of the nation's most vulnerable citizens to be met adequately and effectively.

Problem Stream

What is the main problem for this population? If that were answerable in one concise statement, the disability community would be having a much easier time with passing policy. There are various problems associated with disabilities, let alone autism, let alone adult autism. Some major themes however are very apparent: not enough services; not enough resources; not enough qualified staff; not able to keep up with the burgeoning numbers starting to become very apparent, as well as not enough coordination. The majority of problems has and will always come down to needing more money.

Some indicators that money is a real problem lie in the budget crises illustrated in the Finances/Funding section, as well as interviews of elites, in Chapter Four. The organizations responsible for bringing services to this population do not have the money to do so effectively. They are taking the burden off state institutions and other entities (e.g. homeless shelters, hospitals, churches) by providing care and services however, are not being given the appropriate amount to do so.

With more money, these organizations can then afford to train staff properly and have competitive wages, which would then bring in higher educated and more qualified personnel. With the influx of more staff, more services would then be possible. With better qualified personnel, the client's quality of life would also improve which could lead to less behavior problems, more participation in the community, able to work more efficiently, which all benefits not only the organization, but employers and therefore the state.

As explained in Chapter Two, feedback is also effectual at bringing problems to the surface. Feedback can be illustrated by the elite interviews conducted for this research. The elites—executive director, fundraiser, administrators, board of director, legislative director, advocate, clinical director—who have specialized and particular knowledge in the disability community and the allocation of services to clients, all agree that the lack of money is the biggest problem facing this community.

Following indicators and feedback, according to Kingdon (1984; 2003), the final method of bringing problems to the light is focusing events. It cannot be argued that autism has become more center stage, at the very least, in the media. This is due in part of numerous celebrities revealing autistic family members of their own. The sheer fact that Congress has declared autism an epidemic and a national health risk goes to prove that the dramatically increased rates of autism (as discussed in Chapter One) has become a focusing event to which Congress has begun to pay attention. ("Autism Epidemic", 2002).

Policy Stream

As mentioned before, it has been extremely difficult to acquire one, or even a few, concise and direct goals for the autism, along with the developmental disability, community. As referred to by the legislative director, this group is going to need to come together and hash out a few common goals in order to launch a truly effective campaign. This researcher contends that the subject of autism has had sufficient time of softening up. Those elected and nonelected officials have become aware of the problem and should be comfortable knowing the problem truly exists. One policy proposal I contend that should be floating in the policy primeval soup is the proposal of eliminating the limit on

SSI accumulation. This policy recommendation would benefit not only autistic adults, but other adults with disabilities as well. It will encourage more workability, when possible, which would then allow the individual to pay for more services and save the state money.

Along with the SSI policy proposal, the simple proposal of more money being allocated for this area's direct use is inevitable. Currently, states have the authority over budgeting money to their respective organizations by way of grants. They also budget money to regional centers that are mainly responsible for determining the types and breadth of services needed for individuals with disabilities. Regional Centers pay a specific rate to the organization providing the services per client. The federal government is responsible for the SSI rates.

This researcher is proposing two policy alternatives to allow for more needs to be met. The first policy proposal invites the state to allocate more money to their respective regional centers in order to increase their 'per client' rate. This rate is a set amount per client per day in order to pay for services. As described under Funding/Finances in the California Autism Foundation section in the previous chapter, these set rates paid by the regional center are used to pay for services from an organization, be the organization private or public. These services can include day programs, transportation, and supplemental employment. With the per client rate increased, consumers are able to contribute more to their service providers, whatever the service may be. Considering consumers vary in regards to their needs, their per client rate can be increased in the categorical service they are in need the most. If a consumer only needs minimal transportation but is in dire need of more day services, an increase in the appropriate per client rate would be exponentially beneficial.

Increasing per client rates then brings more money to the organizations providing services. Having a rate increase that directly benefits day programs, supplemental employment, or other services would be able to improve a number of failing circumstances. With more money, organizations would have the opportunity to hire more staff or to effectively train current staff. A rate increase could provide for more competitive wages, which not only increases the opportunities for hiring more qualified personnel but also keeping current personnel satisfied. In addition, a rate increase could decrease the rate in turnover, another serious problem associated in the social services. A happy worker works more efficiently and provides better quality output. With more money, organizations would be able to improve services such as recreation or life skills. They would be able to keep their premises in better condition. They could build or buy more space, especially with the numbers escalating as they have.

With a per client rate increase, more money would disperse into service providers which would ultimately improve quality of life for the disabled individuals. Increasing the per client rate insures the money is spent on specific services and programs along with other instruments that directly benefit the consumers. Considering the funds are being channeled through an agency, state regulations and licensing mandates where and how the money is spent which allows for oversight and control.

An alternative proposal to this recommendation is funneling more money directly to service providers. By giving more grants and investing more funds in organizations, again both private and public, these clients could benefit immensely. Organizations could use the funds, again for many of the same reasons as stated above, in order to bring quality services to disabled citizens. The regional centers per client rate would remain the

same and the organizations would have authority over where and how the money would be spent. As one officer in an organization put it, "Give us the money, we are the ones who know what to do." Funds could be spent on building more and bigger state of the art facilities, training modules for direct service providers, competitive wages which would provide for a more stable work environment by decreasing turnovers, improve existing programs such as day programs, supplemental employment, job and life skills, and recreational activities.

An objection to this proposal could be the lack of authority over spending with private organizations. Private organizations could act unethically and use the funds for personal purposes. There is a potential for consumers to be taken advantage of, a very real and horrific problem disabled individuals unfortunately face every day. However, states could mandate specific directives for use of government grants and have a stipulation that the organization provide financial statements that declare where and how the money was spent. If an organization failed to use the money as directed, fines or penalties would be in order.

According to the criteria for survival: "technical feasibility, value acceptability within the policy community, tolerable cost, anticipated public acquiescence, and a reasonable chance for receptivity among elected decision makers" (Kingdon, 2003, p. 131), these recommendations have the potential to meet these criteria if floated properly in the primeval soup and soften up policymakers. The only foreseeable obstacle would be the tolerable cost. Governments do not like proposing more money or reordering the budget to allow more spending. Nevertheless, as the number of people with autism and other developmental disabilities rises, as it currently is, this problem will no longer be

obscure or irrelevant. The amount of U.S. citizens being born and diagnosed with developmental disabilities has become staggering and services, programs, and policies need to be put in place in order to prepare for the provision of adequate and acceptable assistance to those who are in desperate need.

Another objective should be the coordination and cooperation within the autism community. As stated in Chapter Three, coordination is a severely needed component. Coordination is mostly needed between state agencies such as school districts and regional centers. The school districts have the ability to track individual students, along with vital statistics that can help regional centers find students and families who may not be aware of the services offered. School districts can also be a way of distributing information more effectively to the families, again to help inform families in need of services.

Political Stream

This study contends that the factors in which Kingdon described as essential assets to the political stream are receptive to this particular topic. The appearance of more and more autism centered interest groups and organizations over the last ten years are a direct result of the emerging fervor regarding autism and its need for treatment and services. To name a few: AutismSpeaks (Cure Autism Now) founded in 2005; National Autism Association founded in 2003; Organization for Autism Research founded in 2001; Autism One founded in 2002; Generation Rescue founded in 2004; Treating Autism founded in 2005; and Unlocking Autism founded in 1999, are among others. Not only does this provide evidence for more activity regarding autism research and awareness, it also provides more organized interest pressure.

Unfortunately, as stated in Chapter One, these groups all have their own agenda. They are all fighting to get more services/funding/research for autism but they are all working different angles at the same time, thereby diminishing any pressure on political actors. These groups, along with longstanding interest groups such as the Autism Society of America and the Autism Research Institute, need to work together to define specific goals in order to enact major change for the autism community as a whole. If these groups can combine and work together, they could have enormous clout with the political community and be able to finally see things accomplished.

Coordination between autism advocates and interest groups is also extremely crucial. A major goal for the autism community should be the outlining of specific rank-ordered goals to work towards. With so many groups pulling attention to their single priority, not enough attention is centered on the universal goals of the community. Once this coordination and cooperation has developed, only then will this cause be able to move forward and see actual results be it more government services, funds, schools, research etc.

It can also be argued that autism policy has a place in the current national mood. In conjunction with more and more interest groups and organizations, there are committee hearings in the House of Representatives. In the committee hearing on government reform on April 18, 2002, Congress declared autism a national epidemic. There have recently been nationally televised events for the simple reason of promoting awareness of autism as well as to raise money for research. Autism is present in the national mood.

Finally, the last factor in the political stream is governmental changes. A change in the administration will be taking place within the year and therefore, the agenda will change. Autism has had strides towards accomplishing goals, but with the administration change, significant strides still may be had. In addition, politicians will want to jump on the bandwagon for fear of the backlash from the public for 'not supporting autism.' This also is a window of opportunity.

<div align="center">Policy Window</div>

Perhaps one of the more predictable scenarios that open windows is an administration change. An administration change can be quite beneficial for this community if policymakers can gather proposals to submit and the interest groups can come together with one voice. The autism community needs to become more organized in order to benefit from this window of opportunity.

Autism is part of the national mood. The enormous rise in children being diagnosed with autism as well as media portrayal has provided a focusing event. Elites— people with specialized knowledge and experience in this field—have been identifying problems and doing things to try to bring about change. The public and politicians are well into their softening up period. There is fertile ground in the agenda for the politicians to consider autism proposals.

The open policy window has arrived and needs policy proposals and alternatives. This study attempts to derive some recommendations in order to bring about services to meet the needs of adults with autism. If the policy community does not act fast, this particular window will close and it is unknown when another one will open. It is time to

push for action. There are significant problems facing this population, the timing is right, and policy must be improved.

APPENDIX

SAMPLE INTERVIEW QUESTIONS

The set of questions appearing in this appendix are the general prepared questions for

each interview. If more clarification was warranted or another subject was brought up by

the participant, other questions were integrated as needed.

Questions for organization administrators and officers:

1. What is your position/role here at *(name of organization)?*

2. How much direct involvement do you have with the autistic adults in particular?

3. How do you assess the needs of your adult population? How did you determine what

   programs you needed?

4. In your opinion, what are the most necessary needs of autistic adults?

5. Which needs of this particular population, the adults at *(name of organization)*, do you

   feel are not being addressed?

6. What, if any, obstacles are present in the allocation of needs?

7. Is your organization contracted out by the government? Do they give funds for specific

   services, or do they mandate what services you must offer?

   a. How is your income generated? How much by government and how

   much by private organization?

8. Do you feel government policies, like the ADA, IDEA, or any other similar

   governmental policy has been beneficial for this population?

9. Do you feel that any of the aforementioned policies impede your ability to address the

10. In your opinion, do you recognize any major indicators that the problems mentioned before are now requiring government assistance? Do you see anything happening, in a major way that the government can no longer ignore?

11. Is there anything you would like to see the government doing to help, or make easier, for this organization, or the nation as a whole, to cater to the needs of adults with autism? What recommendations do you have?

Questions for state bureaucrats:

1. What is the trend of policies being passed or discussed regarding adult autism?

2. What legislation is now being debated or talked about for this population?

3. What common obstacles are present for getting legislation passed?

4. What sort of pressures do you feel from various interest groups?

5. What are the common themes you recognize from this community with respect to needs? i.e. day programs, respite, vocational work, etc

     a. Are these themes addressed explicitly in proposed and/or passed legislation?

     b. If no, why not? Where are these needs being addressed?

6. What pieces of legislation, in your opinion, have been most beneficial previously?

7. What recommendations or directions would you propose for future policy?

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42 U.S.C. § 1997 et seq. *The Civil Rights of Institutionalized Persons Act*

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