

Financial Impact on Families of Children with Disabilities

a study by: **Kevin D'Agostino**

Introduction

What types of financial hardships arise from having a child under the age of 18 with a disability? In this paper I will review literature pertaining to this topic and describe in detail the research which I conducted. I examined the financial strains put on families, how and if insurance companies help or hurt situations, families need for assistance, satisfaction with services (occupational therapy, physical therapy, speech therapy), and the overall financial hardships endured by families of children with diagnosed disabilities.

The disability sector has been gaining ground in society since the early 20th century. A major inspiration for the disability rights movement was the U.S. Supreme Court decision in the Brown v. Board of Education case in 1954. The Supreme Court ruled that separate schools for black and white children were unequal and unconstitutional. This decision was a catalyst for progression in rights for disabled Americans. That same year, Congress passed the Vocational Rehabilitation Amendments, authorizing federal grants to expand programs available to people with physical disabilities. The momentum started then and continues now. But, with the abundance of (expensive) resources currently available and an ailing U.S. economy help is needed by these families. My study strives to prove just that. Prior to the start of data collection, I hypothesized that families of children with disabilities were at a monetary disadvantage and were in need of more aid in order to maintain financial stability.

Literature Review

I find this topic to be incredibly relevant in these tough economic times. For example, an article by Joseph Shapiro regarding a family from Nevada who is paying out of pocket for their autistic son's therapy services because the state can't afford to aid the family. Another article out of Nevada tells the story of a mom who re-enlisted with the Army so her son, who was born with a brain injury, could receive proper care. As I will describe later in the paper, the families in which I surveyed have had similar experiences of out-of-pocket expenses and sacrifice. I will also review a research study done on financing health care for disabled children. The study examines healthcare vs. out of pocket expenses and ways to protect families from "catastrophic medical expenses." (Newacheck, McManus, 1988:385).

Another study I looked at evaluates the childbearing of mothers whose first born child has a disability. I will review a social science research study done on the relationship between having a child with a disability and reliance on welfare benefits. Lastly, I will look at a study that examined overall familial problems and issues associated with having a child with a disability. For example, parents not fully understanding the disability their child has, sadness in mothers, and effects on their work and social lives. In this aspect, my research concentrated solely on the child with disabilities' effect on parents occupational status.

The articles and research studies that I have chosen to write about and review are full of valuable information. But, as I will point out, each one is deficient in certain areas. These shortcomings provide a platform for future research and magnify the need to look further into the ongoing social, financial, and familial problems associated with having a child with disabilities.

Reality

The United States is going through some of the toughest economic times since the Great Depression. Unfortunately, no sectors of the country are safe and that includes the healthcare industry; case in point, the Johnson family from Nevada. Joseph Shapiro reports in an article entitled “Recession Hurting Kids with Developmental Delays,” about the Johnsons who have a two year old son with autism named Ben. Due to Ben’s autism he has significant speech and developmental delays. Last September the Johnsons arranged to have nine hours of therapy services for Ben per week through the Nevada Early Intervention Services. The therapists have still not come. The combination of the recession and the growing number of children in need of services has the state telling the Johnson family that Ben’s services will have to wait. For a young child with autism, having to wait is not easy. The purpose of early intervention is to lessen the effects of the disability, so everyday counts. Many times early intervention not only aids the child, but the family too. It is for this reason that the Johnsons felt it necessary to pay out of pocket for Ben’s services. Ben receives applied behavioral analysis (ABA) which helps him build language and social skills. “The American Academy of Pediatrics says that when kids get this treatment early and intensively, many will make substantial gains in IQ scores, language and their ability to learn.” (Shapiro, 2009: <http://www.npr.org/templates/story/story.php?storyId=100293798>). Though they have seen some great improvements in Ben since the start of therapy, it has come at a very steep cost, \$3,000 a month. The reality of the matter is that Ben will need services for many years to come, and the Johnsons don’t know how much longer they can afford it. For the Johnson family, the light at the end of the tunnel may be the stimulus bill that just

passed. The stimulus bill includes more money for the federal part of the early-intervention program. (Shapiro, 2009).

In another story written by Joseph Shapiro, the title tells all: “Mom Re-Enlists to Get Treatment for Disabled Son.” The Spahr family is anticipating similar problems in Nevada. Their son Owynn was born with a brain injury due to Emily (Owynn’s mom) being infected with cytomegalovirus during her pregnancy. “He can’t do things that should come easily — like raise his head and keep it up, or keep his balance. He’s going to need a lot of therapy.” (Shapiro, 2009: <http://www.npr.org/templates/story/story.php?storyId=100158007>). Where will the money come from for all of the vital therapy Owynn depends on? As we know from the Johnsons’ story, the state can’t afford to fund his therapy, so Emily made the tough decision to re-enlist with the Army in order to get her son the care he needs. While she is going through the process, Owynn is receiving physical therapy sessions twice a week, only part of the therapy he fully needs. For this the Spahrs are going through Nevada’s Medicaid program, which has also made significant cuts in paying therapists who treat children. Owynn will continue with his twice a week physical therapy until his mom puts her life on the line for him to receive more comprehensive therapy services that the state cannot provide.

Harsh realities such as the Johnson and Spahr family situations point out the seriousness and magnitude of the current economic situation and its relation to the disability sector. Hearing their experiences makes me wonder how many other families with children with disabilities are living under similar circumstances. These two stories are powerful, but the study that I conducted has similar sentiments on a larger scale. To

quantifiably study numerous families of children with disabilities and the effect these children have on their financial situations may be profound in further proving the need for more government programs and aid.

Decisions

Unfortunately, birthing and rearing a child with a disability creates a whole new life for families. In this new life, many important situations arise and families find themselves at a crossroads having to make incredibly difficult decisions. “One’s Enough for Now: Children, Disability, and the Subsequent Childbearing of Mothers” by Maryhelen D. MacInnes is a mixed-methods study that chronicles one of these difficult situations. In her research, MacInnes reviews the 1993 National Health Interview Survey, the 1995 National Survey of Family Growth, interviews with caregivers of children with disabilities, and she draws upon rational choice theory.

Over the past few decades the trend of having a family without children has been on the rise. This is due to the increasing acceptability of the behavior, increasing availability of contraceptives, and increasing opportunity to abort. Because of this trend though, it is safe to assume that families who are crossing that threshold and having children, want them. With that said, having a child is a huge responsibility that can be overwhelming at times. “An ideal mother will invest considerable time, energy, and money in raising her children...” (MacInnes, 2008: 759). When raising a child with a disability the ordinary stressors that accompany child rearing are largely magnified. Earlier research shows that raising a child with a disability can strongly impact families, leading to higher divorce rates, lower levels of labor force participation, and poorer well-being for caretakers. (MacInnes, 2008: 758).

Despite discovering all of this valuable information, MacInnes saw an opportunity to research the impact of having a child with a disability on mother's subsequent childbearing. Her quantitative results combine the National Health Interview Survey and the National Survey of Family Growth. She compares demographics between first born children with and without disabilities. I created a chart which summarizes what MacInnes found. Each percentage indicates the majority and by how much in each category.

Demographics	1st Born With Disability	1st Born W/o Disability
Male	+12%	
Female		+12%
Under 20	+6%	
20-29	+1%	
30+		+7%
More than H.S. degree		+4%
High school degree	=	=
Less than H.S. degree	+4%	
Un-employed	+8%	
Employed		+8%
Not married	+6%	
Married		+6%
Above poverty line		+8%
Below poverty line	+8%	

This research shows that there is a significant association between social disadvantage and disability in children. Having a child with a disability can only further prevent a family from rising above the poverty line, and deter that family from having more children.

Her qualitative research consisted of 24 interviews, 22 with mothers, 1 with a father, and 1 couple. The majority of the children with disabilities were male. The respondents ages ranged from 22-47, and the children's ages ranged from 3-15. The disabilities included cerebral palsy, muscular dystrophy, general developmental delays, and spina bifida. Ten of the twenty four respondents were unemployed and the fourteen who were employed worked less traditional jobs that would allow them the necessary time off to care for their child. Most parents spoke of the amount of time and energy it took to meet the needs of their disabled child and couldn't imagine having another child to care for as well. Not all parents fully agreed. Some parents did have more children, but waited about 8 years. (McInnes, 2008).

Maryhelen D. McInnes' research does show that having a 1st born child with a disability does in fact influence parenting and decrease subsequent childbearing. But, as she states, "The observed effect is only moderate, although this is likely a conservative estimate of its impact." (McInnes, 2008: 768). Family dynamics and individual complexities play a major role in the decision to have another child as well.

McInnes' research study gave me some valuable insight into the world of families who have children with disabilities. The interviews she reported on filled me in on the financial worries that families have and the difficulties in finding employers who are willing to adapt to uncontrollable situations. The most valuable skill that I gained from

this study was how to read and identify survey information. I used confidential surveys in my research, and it was helpful to get some idea about how to read into completed surveys and come up with logical insight. McInnes' research did lack in certain areas. I thought that in her quantitative data, some of the relationships could have been spurious. She made connections between being below the poverty line, and unemployed with having a child with a disability. Though I would agree with this concept, the lifestyle that these individuals choose to live could cause these effects as well. I would have also liked to hear about equipment needed, renovations necessary to house the child, therapy services needed, transportation costs, schooling costs, etc. McInnes seemed to generalize that having a child with a disability entails added responsibility, attention, and time, which it does, but I would have liked her to be more specific. Overall, McInnes proved her point and in doing so helped me better understand the logistics of research methods.

Another incredibly tough decision a family of a child with a disability might face is the need to receive cash assistance from programs such as TANF. TANF is temporary assistance for needy families, and is commonly used by families who can't afford expenses associated with their child's disabilities. Peter D. Brandon, Sandra L. Hofferth, and Dennis P. Hogan did a research study testing the hypothesis that having a child with disabilities will act as a barrier to future independence and push families who previously received government assistance back to relying on them. Their article is entitled "Do Disabilities in Former TANF Families Hasten Their Return to Cash Assistance?"

In 1996 welfare programs such as TANF were reformed. As a result of these reforms, welfare roles were reduced and work participation among TANF recipients was on the rise. As one could imagine though, having a child with a disability not only adds

financial burdens, but also interferes with employment. This is a root cause of families who worked their way off welfare assistance needing to return to their reliance on them.

“The primary source of data for this study is the 1996 Survey of Income and Program Participation (SIPP), a 48-month longitudinal, nationally representative, stratified random sample of the US population.” (Brandon, Hofferth, Hogan, 2007:533). For four years respondents were interviewed every four months. Questions pertained to family income, number of children, number of family members with a disability, extent of disability, and characteristics of the mother (age, education level, race, marital status, employment status).

The researchers found that mother’s demographics play a significant role in determining her re-entry to TANF benefits. Young, single, un-employed, black mothers had the highest re-entry rates when looking at demographics. More importantly, when you added a child with a disability to the equation, the numbers nearly doubled. The largest percentage of re-entry was from families who had a child with a disability whose functional limitations included self care; children who rely fully on a caregiver for almost all needs. (Brandon, Hofferth, Hogan, 2007) Obviously a child with needs such as these requires 24/7 attention and can heavily influence a parents employment. “So, we conclude that unless families with disabilities receive an array of services early in the post-TANF period, they are highly likely to return to TANF and gradually populate the hard-to-employ TANF caseload”. (Brandon, Hofferth, Hogan, 2007:540).

A study such as this lays a solid foundation for my research. I examined how families are financially impacted by children with disabilities. One way they can be affected is to be at a desperation point and need to rely on government assistance such as

TANF. This research in particular is effective in proving a point because these were families who needed financial assistance, one way or another worked their way off the assistance, and then because of having a child with a disability had no choice but to go back on. The authors of the article suggest that government officials review their findings and add some type of clause or added benefit for families in need with disabled children. Great idea, but I wish they would have suggested some specific examples. Should families of children with disabilities be pardoned from the employment mandate? Should they receive more depending on the severity of the disability and the equipment needed? I would answer yes to both of these questions, but the important question is will the government realize the need to address specifically families of children with disabilities? My research answers this question and more.

Cost

“Financing Health Care for Disabled Children” by Paul W. Newacheck and Margaret A. McManus aims to examine health care use, charges, and out-of-pocket expenses. The researchers used data gathered from the 1980 National Medical Care Utilization and Expenditure survey (NMCUES). They compared use of medical services and associated costs for disabled and non-disabled children younger than 21 years old.

The NMCUES “was designed to produce detailed information about the nation’s health status, patterns of service use, charges for services, and methods of payment.” (Newacheck and McManus, 1988: 386). The survey/interviews were conducted over a period of 1 year and 3 months. 17,000 persons were interviewed five times throughout the process. Also, heads of households were asked to keep private notes of illness episodes, health care use, and charge information.

In 1980, 4.0% of children under the age of 21 had prevalent activity limitations. Of this 4% the majority were males, aged 16-20, white, and above the poverty level. “The most frequently reported conditions were mental disorders, and nervous system disorders including mental retardation, neurotic and personality disorders, epilepsy, and cerebral palsy. (Newacheck, McManus, 1988:387).

Their research found that children with disabilities used much higher levels of hospital services than other children. Hospital admission, days spent in the hospital, physician visits, non-physician visits, and prescribed medications were all at-least doubled for children with limitations/disabilities than those who were not limited. Disabled children were three times as likely to spend 8 or more days in the hospital.

Total charges for health services were \$1,239 per disabled child compared with \$429 for typically developing children. On a macro level, disabled children accounted for \$21.9 billion in charges for health services, in 1980. Hence, the 4% of children and youth who had a disability accounted for 11% of total health care expenditures for the less than 21 year old population. (Newacheck and McManus, 1988).

Out-of-pocket expenses were much higher for children with disabilities than those without. In fact, on average the money paid directly by the family was doubled for disabled children. The majority of these costs came from prescriptions. Seven percent of the out-of-pocket costs stemmed from hospital stays, but 59% for prescription medications. (Newacheck and McManus, 1988). Basically families who have a child with disabilities are paying out-of-pocket for the difference of care and prolonged hospital stays that exceed what a typically developing child gets.

The authors briefly reviewed some of the up and coming programs that were being created to protect families who had children with disabilities; for example, federally sponsored catastrophic health expense protection for disabled children. In this case the government would subsidize costs of health care for families of disabled children with high out-of-pocket expenses. The government assistance would kick in when out-of-pocket costs exceeded \$1000 and/or 15% of a family's total income. (Newacheck and McManus, 1988).

This research study was rather outdated, but the ideas presented are still relevant today. Children with disabilities require more health care on many levels, and in order to receive the proper care and afford the bills, government assistance is necessary. Results may be skewed because of the year the study was done, but presumably the numbers have been inflated to fit today's standards. My study achieves a more up to date outlook on medical costs associated with a child's disability and how those costs affect their family. In 1980 therapy services were not as widely used, and were not as advanced as they are today. Therapy services are a crucial part of increasing independence and functionality in the life of a child with a disability. But, these services usually have a steep price associated with them. My study includes therapy costs and how efficient the insurance companies are in picking them up. The authors expressed some issues in their study, for example partial non-response to specific questions. Fortunately, this was not a significant problem for me.

Overwhelmed

Shock, denial, depression, suffering, guilt, indecision, anger, and shame are some of the words used to describe parent's reactions to learning their child has a disability.

Esine Sen and Sabire Yurtsever feel that parent's emotions can be grouped into three categories: primary, secondary, and tertiary. During the primary stage parents go through a state of shock, secondary leads to feelings of guilt, and in the tertiary stage parents begin to accept the situation and look for ways to adapt their lives to fit the needs of the disabled child. Issues that arise within families of children with disabilities are not limited to financial aspects.

In an article written by Sen and Yurtsever, they describe their descriptive research study which was carried out in one public and two private rehabilitation centers. The data was collected through questionnaires that were distributed to mothers of 103 disabled children whose ages ranged from 3-18 years. The questionnaire consisted of 50 questions. "The first 22 questions are directed at determining the socio-demographic characteristics of the family and disabled child; and semi-structured questions 23-50 are directed at determining the difficulties faced by the family (difficulties experienced in daily care, financial difficulties, psychological difficulties, and difficulties experienced in their social lives) and the support that they have received and want to receive to help with the difficulties they experience." (Sen and Yurtsever, 2007: 242).

The most staggering statistic that the researchers found was that 94.2% of mothers of children with disabilities were unemployed. This obviously creates a significant financial impact on a family. Mothers who indicated difficulties in caring for their child differed by disability. For example, 80.4% experienced difficulty with children with cerebral palsy, 68.6% reported difficulty with children with intellectual disabilities, and 70.6% of mothers had difficulty caring for their children with autism. (Sen and Yurtsever, 2007). Difficulties in home care included feeding, dressing/undressing, bathing,

carrying, communication, and continuous monitoring. Due to these ongoing difficulties, mother's emotions were affected. 57.3% developed deep sadness, 54.4% were overwhelmed, 36.9% had anger, and 7.8% experienced loneliness. "Almost half of the families (47.6%) of all of the disabled children experienced financial difficulties: 49.0% of the families with Cerebral Palsy children, 57.1% of the families with intellectually disabled children, and 23.5% of the families with autistic children experienced financial difficulties." (Sen and Yurtsever, 2007: 244). Many of the families who had financial struggles were fortunate enough to receive assistance, but, 96.6% of mothers reported receiving the support from close relatives rather than public and/or government agencies.

I chose to review this article because it is important to not focus solely on financial burdens put on families who have a child with a disability. The issues that arise branch out to all aspects of family life including, but not limited to, their bank accounts. The writers succeed in statistically pointing out the overwhelming emotions and difficulties families face on a day-to-day basis. Though not mentioned in my review, Sen and Yurtsever do a thorough write up on their procedures. They discuss informing the participants and then receiving permission on various levels. This was unique to this article and gave me helpful insight to what my procedures would eventually entail. Also, this article gave me a more broad perspective on the lives of these families. A downfall of the article was that the research was conducted in Southern Turkey. Though it does not affect the accuracy of the data, comparing results to the United States makes for some unauthentic associations, such as certain cultural differences. Despite it being from a different country, I gained some very valuable information and insight that was applied in my own research.

Reviewing these articles gave me a valuable knowledge background, tips for conducting a research study, and an outlook that a current study on how families are financially affected by their child or children with disabilities is needed.

Methods

My research study examined the financial implications on families of children with disabilities. Prior to data collection I hypothesized that having a child or children with diagnosed disabilities would in fact significantly impact a family's financial stability. A null hypothesis to this would state that having a child or children with diagnosed disabilities would have no affect on families' financial stability. Post data collection, I reject the null hypothesis. My data shows that having a child with a diagnosed disability does impact a family's financial situation.

In order for me to examine this topic, I chose to create an online survey. I felt that a survey would be the most effective way to investigate the statistical association between the cost of having a child/children with disabilities and the families ability to maintain monetary stability. By using the online survey method I was able to reach networks that were outside of my immediate area. This method allowed me to take advantage of networks along the entire east coast. The online survey also made it as convenient and flexible as possible for my respondents. They were able to answer the questions on their own time and in privacy which avoided issues such as the Hawthorne Effect. Some questions were personal; by using this method I was able to assure my respondents that their information would be kept confidential. Also, some of my questions involved specific monetary amounts which may have required some

investigating of bills, statements, etc. on the part of the respondent. My method gave respondents the time necessary to answer questions comfortably and accurately.

My research was somewhat unique in the sense that I had a very specific population in mind. Every individual who completed my survey needed to have at-least one child with a diagnosed disability. Because of this, I did non probability sampling within a descriptive study. Due to the specificity of the population I chose, response rate was low. Despite the low numbers I can confidently say that my data is reliable (consistent) and valid (accurately measured what was intended); quality not quantity.

For my study the independent variable was a family who had at-least one child with a diagnosed disability. The dependent variable was the family's financial situation. I was careful to rule out spurious or rival explanations such as the family being in financial trouble prior to the child with disabilities being born. If the family had financial trouble prior to the child with disabilities being born, I sought to show that the cost of having that child with disabilities could only make matters worse without the proper aid. I strived to prove these points by asking series' of questions regarding health insurance, health insurance premiums, therapy related services and out-of-pocket payments, availability of supplemental and/or government aid, affect the child with disabilities has on their parents occupation, employment status, income, affect on decision to have more children, familial sacrifices made, marital status, and if having a child with disabilities had an overall negative affect on financial well-being. For the most part, the questions were individualized and intended to represent a foundation of annual costs associated with family life while raising a child with a disability. Some questions were open ended,

some had optional comment boxes, and my purpose of doing this was to gain some qualitative data to back up my quantitative numbers.

My intent is to show that there are significant costs that come with raising a child with disabilities and making the most of the resources available for the child. Along with the added costs come financial woes for the family. My research is advocating for more help, aid, funds, grants, scholarships, attention, and money for families of children with disabilities in need. Children with disabilities need services and they need specialized equipment but the families need help in providing these necessary tools for everyday life.

Throughout my research experience my major problem was survey participation. With more time, I could have at-least quadrupled my response rate. But, as stated early despite a low response rate, I am confident that my results are legitimate and paint an accurate picture of the current economic status of families of children with disabilities. Post data collection I am still comfortable with my design and procedures.

Results

Quantitative Data

To begin explaining my findings, I'll start with a synopsis of demographic factors. The majority of respondents were married couples, with more than a high school education, earning between \$50,000 – \$74,000 annually, and had a child with a diagnosed disability between the ages of 2 – 5 years old. Table 1 refers to demographic features.

Table 1: *Demographics*

Gender of Child with Disability		Age of Child with Disability		Family Income		Parents Edu. Level		Parents Marital Status	
		0-1	3.2%	>\$15,000	3.1%			Married	90.9%
Male	58%	2-5	54.8%	\$15,000-\$29,999	9.4%	>High School	3.0%	Not Married	0%
Female	42%	6-10	22.6%	\$30,000-\$49,999	9.4%	High School	6.1%	Divorced	6.1%
		11+	19.4%	\$50,000-\$79,999	40.6%	<High School	90.9%	Widowed	0%
				<\$75,000	37.5%			Long Term Rel.	3.0%

The majority of respondents (93.9%) are insured, 0% were uninsured, and 3% of the children with disabilities have child Medicaid. I was pleasantly surprised to find that none of my respondents were without insurance, at-least for their children. Another positive surprise I found was that 61.3% of the insured respondents did *not* see an increase in premium after adding their child with disabilities to their plan. In my experiences I have heard horror stories of insurance company's almost forcing people to cancel their plans because of the premium increases they incurred after adding their child with disabilities.

Next, I examined the relationship between therapy services received, out-of-pocket payment for therapy services, and satisfaction of therapy received. Therapy related services include occupational therapy, physical therapy, and speech therapy. Therapy related services are represented in table 2.

Table 2: *Therapy Related Services*

Receive Therapy?		Pay out-of-pocket?		Services Adequate?		Rate Services	
						Excellent	20%
Yes	83.9%	Yes	40.6%	Yes	60%	Very Good	50%
No	16.1%	No	46.9%	No	40%	Good	20%
						Fair	10%
						Poor	0%

Again, some pleasant surprises regarding therapy related services. As I expected the majority of the children received therapy related services. But, it was pleasing to see that the majority did *not* pay out of pocket, found services adequate, and rated services as very good. This shows that aid is being dispersed for necessary therapies but many are still liable for paying out-of-pocket. I will breakdown the out-of-pocket monetary amounts in my qualitative data section.

Another aspect of life for families of children with disabilities affected is employment. Though 72.7% are currently employed (27.3% unemployed), most find their ability to work is hindered due to their child's needs. 77.4% reported that their ability to work was limited. Limited is a broad term that can mean their child's demands consume much time that could be devoted to work, employers are not willing to work around their busy schedules, or there are not child care services that can cater to their child's needs. Less work and added expenses (56.7% report added transportation costs) lead to a reliance on government assistance (see table 3).

Table 3: *Available Aid*

Currently Receive Aid		Rate Aid Available		Added Stimulus Benefits?		Should Gov't do More?	
		Excellent	6.3%				
Yes	41.9%	Very Good	12.5%	Yes	15.2%	Yes	81.3%
No	58.1%	Good	31.3%	No	84.8%	No	18.8%
		Fair	40.6%				
		Poor	9.4%				

Here we begin to notice some of the lack of aid given. Less than half of respondents are receiving aid and over 80% feel government should be doing more. There are a lot of families who are being left to deal with the expenses by themselves. By the looks of the data, the aid being given is *not* up to par; the majority gives it a “fair” rating. More must be done.

Having a child/children with disabilities can add many stresses to family life. Lastly, I asked a few broad questions regarding individual family dynamics, as seen by table 4.

Table 4: *Family Dynamics*

Has having a child with a disability affected decision to have more children?		Has your family had to make any monetary sacrifices due to the added cost of having a child with a disability?		Has having a child with a disability negatively affected your financial status?	
Yes	61.3%	Yes	67.7%	Yes	74.2%
No	38.7%	No	32.3%	No	25.8%

Qualitative Data

Along with my surveyed quantitative data, I collected some qualitative responses from some questions and allowed comments on others. In order to properly examine the qualitative data I used a content analysis approach. I systematically studied responses given and looked to identify key words, key concepts, common themes, and consistent trends.

The first open ended question stated: Has your family had to make any monetary sacrifices due to the added cost of having a child with a disability? The overwhelming answer to this question is yes. The responses I read were saddening. All respondents

have made incredible sacrifices in order to properly support their child/children with disabilities. Families have diminished their savings accounts for their children to have surgeries, obtain necessary equipment, doctor visits, and therapies. The greatest sacrifice I found with the majority of respondents was giving up work. Many reported moving from two incomes to one, switching from full to part time, and in some cases leaving their jobs all together to better the lives in their children.

Unfortunately, when asked if families had received any added benefits from the 2009 stimulus package, most have not. It may be that it's too soon for benefits to kick in. But many seem to not know if they're even entitled to any added benefits. One respondent answered "The stimulus package seems to have bypassed us. We currently receive no monetary benefits, except a respite check of \$33.00 monthly from Community Partners. From any federal, state or local organizations, we are not sure if we qualify."

I asked respondents to supply the dollar amounts that they pay out-of-pocket annually for services and a lifetime cost of equipment for their children with disabilities. The numbers were staggering. Annual out-of-pocket payments for related services ranged from \$800 - \$10,000. The average family within my study pays \$3,278 annually for their child's therapy related services alone. Many respondents reported cutting therapies and other extra curricular activities once insurance stopped covering them. The lifetime cost of specialized equipment ranged from \$1,000 - \$100,000 and the average lifetime cost of equipment for my respondents was \$26,000. Again, many families report wanting and/or needing updated equipment but not having the finances or support to do so.

Finally, I asked respondents in general, has having a child with a disability negatively affected your financial status? It was obvious that almost all of the families were affected one way or another. The most common trend I found though was a mind set of selflessness. Parents didn't want more money, aid, and benefits for themselves they wanted it strictly for the kids. They stated not caring that they can't go on vacation and out to dinner, they just wanted their children to receive an education, therapy services, the necessary equipment, and most of all a chance at a quality life. What follows are some excerpts of what families had to say:

“Due to our daughter's condition, I am unable to work. We are on a single income with everyday household expenses and medical costs ie: non-covered seizure medications, handicap van, etc. We are now learning that prescription medications that were once covered by Medicaid are no longer being covered due to the deficit. Also, we pay very high property tax but can only have one income. We feel very strongly that state should offer a property tax discount to families with handicap members. The state offers a discount for veterans that are or are not disabled...that doesn't make sense at all, they can work-those that are not injured/disabled....”

“We go into our savings to help buy equipment.”

“I feel the government should provide my son with more quality and quantities of services, not me with more money. Really give EVERY child a top quality education and let us earn the living to give him a quality.”

“I left a good paying full-time job (with benefits) to care for my son. My husband is self-employed and doesn't have a steady income-especially in this economy.”

“We had a pretty good amount in savings and a lot of equity in our home before my son got sick, but we have used up all of our savings and maxed out our home equity over the last several years to cover medical and living expenses.”

“Less money from the government, not enough help from the schools. We have to pay for an advocate at the IEP meetings to ensure our child gets the help he needs.”

“Financial help for those with very involved children with disabilities. Money is needed for meds, wheelchairs, accessible vans, medical equipment/beds, renovating houses to accommodate the child etc...”

“Same as above....all the added medical procedures and care that families with typical children do not have.”

” Our financial picture/status is completely different than before Sarah was born (2002) I am sure that would be true in some respect anyways because having a child is expensive, but reducing my work time, traveling to Boston for 4 1/2 months while she was in hospital, and traveling to Boston, Concord, Manchester, Exeter, Bedford etc for appointments does have an financial impact.”

Discussion

Are families of children with disabilities financially impacted? Absolutely. But, this project brought reality to that theme. Its 2009 and the United States is in, what the New York Times has called “The Great Recession”. The disability sector seems to have been a target for budget cuts. The families I studied are the proof. Families are struggling and are in need of aid no matter where it comes from. Unfortunately, currently

it doesn't look like President Obama's stimulus package has been the saving grace some families had hoped for. Maybe, hopefully, time will change that.

My project succeeded in further demonstrating that families of children with disabilities are financially impacted and are in need of a financial boost. But, my study also had many shortcomings. Let's face it, my response rate was low due to the specificity of the target population. While sorting through data I realized there were many more counter questions I could have asked to dig deeper into the responses I received. The deficits in my research open doors for further future research. It would be great to see a comparative study between families of children with and without disabilities. That comparison could significantly multiply the magnitude of the results I found. Also, to do a panel or cohort study, follow groups or families over a period of time to see how their lives are affected and to see changes take place over time would be interesting. Lastly, many of my respondents were in a high income bracket and they are still struggling. I would like to limit or separate a study to lower income families of children with disabilities and see how they survive day to day life.

The progress made since that fateful Supreme Court decision in 1954 that propelled the disability sector and gave it wings has been tremendous. Let's not stop that upward movement now. Let this project be, at-least a small, eye opener. More help is needed for families of children with disabilities. They're struggling to find time to work, find money to finance equipment and services, and like one respondent said give their children a *quality* education.

