The Economic Impact of Autism Spectrum Disorder; The Parents Perspective

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Abstract

In the US and many other countries, more children are being diagnosed with Autism Spectrum Disorder (ASD) than ever before. The treatment, management, and diagnosis of ASD all carry a variety of associated costs for parents and society as a whole. This study seeks to better understand the impact these cost have on parents and their children with ASD. Tension has developed between parents and healthcare providers in terms of what the providers will cover and to what extent. To obtain the parental perspective, an online survey inquiring about parents’ opinions and experiences was sent out to a number of ASD support group leaders and organizations associated with ASD. This survey covers what type of care children are receiving, the cost of this care (by insurance, public health and personal resources), and the impact that financial considerations ultimately have on care. From the results of this survey, three profiles were developed based on health care coverage from, public health insurance, private health insurance, and personal funds. Participants were analyzed based on their report of how finances affected their child’s care. The results show both similarities and differences between the three profiles as well as positive and negative affects. The possible applications for this research are, to provided more effective care and funds for ASD, bridge gaps between healthcare providers and parent and to increase support and much needed information to parents of children with ASD.
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The Economic Impact of Autism Spectrum Disorder; The Parents Perspective

Grabbing large bags of M&M’s from the cabinets for breakfast, pouring any container with liquid down the sink, smearing feces on every available surface area are just some of the quirks that Ian, a 19 year old with severe Autism, has developed. In the day-to-day care for Ian, his parents seek to maintain happiness, to avoid major meltdowns, and to be as stress-free as possible. If it were not for the extra help Ian’s parents receive from a Medicaid-funded caregiver, the task of caring for their son would be next to impossible. His mother speaks candidly in her blog post about the great struggles and costs they face, verbalizing their concern that the state will fail to recognize their need for financial help. With this added aid from the Medicaid-funded caregiver, Ian’s parents are occasionally able to take a moment to relax and rebuild strength so they can continue to care for their active, high maintenance son. Although Ian’s parents have unconditional love for their son, they also seek out ways in which they could improve the situation (Katie, 2010-2011).

Autism presents itself in different forms and to different degrees of severity. All manifestations of Autism are encompassed under the umbrella term Autism Spectrum Disorder (ASD), which includes Autistic disorder, Asperger syndrome and Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS). In short, ASD is a developmental disability that significantly affects the social interactions as well as the communication of individuals (DSM IV, 1994). These features impact family dynamics, with varying degrees of attention and structural changes needed in order to provide the best possible environment for the child. There is not one set therapy or treatment regimen that works with ASD. Thus, treatment regimens vary on their degree of effectiveness for
each individual (Autism Society). Individualized plans allow each child with ASD to discover what works best for their personality and lifestyle. Some leading therapies for ASD focus on the main features of the disorder; communication skills, and social interactions. Behavioral therapy seeks to reduce unwanted behaviors while reinforcing desired behaviors (National Institutes of Health, 2011). With Ian, his parents often use jellybeans to reward his good behaviors, such as sitting still for a haircut. Speech therapy addresses the affects that ASD can have on communication skills, and physical therapy seeks to improve motor skills (National Institutes of Health, 2011). It is important for parents and health care providers to take the situation and needs of the individual with ASD into careful consideration when developing their individualized plan (Autism Society).

Often times parents take on the role of being their child’s care coordinator; managing appointments, investigating which therapies work and which do not, and fighting health insurance to cover the many different doctor and therapy appointments for their child (Carbone, Behl, Azor & Murphy, 2010). Most parents will do anything in their power to help their child reach his or her fullest potential. This typically entails trying every possible form of therapy, seeking medical advice, and researching ways to deal with the wide range of issues that arise when raising a child with ASD (Rice & Bellin, 2009). On the other hand, parents may not adhere to treatment regimens prescribed by physicians (Moore & Symons, 2009). This could be due to a lack of trust between the parents and the physicians, where the parents feel as though they are a better judge of what is best for their child, or it could simply be a lack of time, patience, motivation or energy to stick with a strict treatment regimen.
The following serves as a brief overview of the healthcare system in relation to ASD. It should be noted that this in no way serves as an accurate representation of the healthcare system as a whole, due to its variability. In terms of Medicaid (for lower income individuals), most regulations and allocations of funds are left up to each state to determine what care is and is not covered. Both private and governmental insurance companies are also regulated state by state and vary in what they will and will not cover. Health care providers are partial to absolutes, in that they categorize claims as billable or non-billable. However, with the diagnosis of ASD or other psychological disorders there are far fewer absolutes and greater individual differences in terms of symptoms, care, and treatments. Parents report that insurance companies often state that a claim is “not medically necessary” as their reason for denying coverage of therapy sessions (Konrad, 2010).

Previous research by Michael Ganz (2007) found that expenditures involved in caring for ASD consist of direct costs, both medical (9.7% lifetime cost) and non-medical (31% lifetime cost), such as medications, doctor visits, therapy sessions and care facilities, and indirect costs (59.3% lifetime cost), such as loss of job, and household and individual productivity. In total the annual societal cost of caring for a child with ASD in the United States per capita was estimated at $3.2 million and for an entire birth cohort of individuals with ASD about $35 billion dollars (Ganz, 2007). To put these numbers in perspective, the average lifetime health care cost for a normal American is $316,000 per capita, where as ASD lifetime health care cost is double this amount at $623,000 (Alemayehu, & Warner, 2004). These expenses are paid for by a number of sources such as, private insurance companies, Medicaid, and the parents’ private funds. One of the
The greatest challenges families face is receiving coverage from their health insurance providers for any treatment that is not seen as medically necessary (Konrad, 2010). This lack of financial support, along with the limited resources available from both governmental and private systems, limit individuals with ASD from being able to live to their fullest potential. This potential could be obtainable if financial limitations on health care needs and necessary treatments were reduced or eliminated.

With the growing cost and diagnosis of ASD also comes a growing field of research seeking to understand and find a cure for the disorder. An issue of growing importance is the economic impact of ASD on the individual, their family, health care providers, and our society. Individuals with ASD are influenced by the environment and the caregivers they interact with. Families deal with the day-in and day-out joys and struggles that come with having a child with ASD. Similarly, health care providers are also impacted by the growing number of children filing through their offices. This requires them to devote more time, money and effort towards ASD. Our society benefits when a child with ASD is able to improve, and develop key skills, this enables them to better function within our society. Without the therapies and treatment regimens, these children, in the long term, will burden rather than benefit our society. Thus, it is imperative that further research on this economic impact is explored. The proposed research question for this study seeks to understand how financial considerations impact the treatment of children with ASD, from the parents’ perspective.
The Economic Impact of ASD

Method

Participants

In total 29 parents of children with ASD responded to this online survey. They were contacted through ASD support group leaders and organizations. The mean age of the parents was 40 years old, 2 were single, 24 married, 2 divorced or separated and 1 spouse deceased. In terms of location 12 lived in a rural setting, 10 in suburbia, and 7 in urban areas. The average age of the children with ASD was 12 years old, 24 males and 5 females. Of these children 4 were low functioning, 11 moderate functioning, and 14 high functioning. There were 16 diagnosed with Autism, 7 with Aspergers, 5 with Pervasive developmental disorder not otherwise specified (PDD-NOS), and 1 other (comorbid with ASD).

Online Survey

The online survey was first posted on various websites, forums, and social networking sites associated with ASD, however this avenue proved to be rather fruitless. In order to contact parents more directly, ASD support group leaders and organizations were sent an email (refer to appendix 1) requesting their participation, information about the research, and a link to the survey. The online survey (refer to appendix 2) started with an informed consent, ended with a debriefing form and consisted of demographics ASD history (eg. child’s functioning level and diagnosis), past and present services funding of services (eg. percent covered by public health care, private care or personal funds), and financial impact (eg. how finances affected care and treatments).
Results

To best answer how financial considerations impact the treatment of children with ASD from the parents’ perspective, two survey questions were analyzed. The first of these two questions asked parents to estimate what percent of their care was covered by public health care, private health care, or personal funds. Based on where the majority of funds for health care cost fell, the parents were categorized into three groups; public, private and personal funds. Once they were placed into these categories their responses to the second question, asking parents to describe how finances have affected the care and treatment of their child, were examined. To narrow the focus further, the responses to the second question were categorized either having a positive or negative effect and if it was a personal (effecting the child) or financial effect. A profile was then developed for public health care, private health care, and personal funds. These profiles show the common struggles and issues the parents all face, as well as the different experiences they encounter as a result of different forms of health care coverage.

The profiles developed out of this process show similarities and differences in terms of the positive and negative influence finances have had on their child’s care. Frequent responses found in all three categories show that financially parents’ personal funds are limited, they take on debt, there is a decrease in household income and there is added stress on the family. All of these are sacrifices parents make to provide care for their child. Parents also expressed that finances limited or prevented their child’s access to treatments. Despite these and other negative effects parents have experienced with finances, they feel that the growth of their child makes the sacrifices worth it.
Public health insurance is often provided for lower income families who are in need of health care coverage. The results of question two show that Medicaid is helpful in terms of their coverage for things such as medications, testing and routine care. Parents also expressed how beneficial grants and waver programs were financially. In terms of negative effects on finances, Medicaid does not cover certain treatments, such as music therapy, or preventative care. The Children are also limited due to finances, in that they are unable to receive the support needed to develop job skills. Overall, it seemed as though the only treatments available to children with primarily public health care were those covered by insurance, any treatments or needs beyond this were limited or unobtainable.

With private health insurance, parents were more likely to receive a helping hand with payments from others, such as hospital foundations, family, and the kindness of strangers. In contrast to the public health care, parents were able to provide therapy and support for their child, who, as a result, obtain a degree from community college, found a job and gained a level of independence. One major set back with private health insurance is that there is little to no coverage for ASD, which requires parents to pay more out of pocket or spend time fighting for coverage from the insurance companies.

Parents, who primarily paid out of pocket for health care cost, expressed that finances were not a barrier with providing care for their child. This is a stark contrast to the struggles faced by the individuals with primarily public health care, who are limited by finances and what Medicaid will and will not cover. These three profiles provide different windows into the financial issues parents face with providing care for their
children with ASD. (For a complete list of participant responses to the second question please refer to Appendix 4).

Discussion

The purpose of this study is to gain a better understanding of the cost involved with providing care for a child with ASD, from the parents’ perspective. The results of this study reveal three main themes associated with these cost. The first theme is sacrifice, which affects the lives of parents and families of children with ASD in various ways. Previous research by Ganz (2007) reflects the financial cost of sacrifices such as the parent and child’s loss of productivity or income. Such financial sacrifices may increase the stress on the family.

The second theme expressed by parents is limitations. These limitations vary in form, and degree of affect, from limits set in place by the insurance providers for what treatments they will and will not cover, to the financial limits of paying for care and ASD treatments that are not covered by health care providers. These limits conflict with previous research which found that parents are willing to do anything in their power to help their child reach his or her fullest potential (Rice & Bellin, 2009). This conflict may result in parents’ taking on debt in order to pay for these costs. Further research is needed to determine what affects these limitations have on the financial cost of ASD.

The final theme reflects on the positive aspects of ASD care and treatments. Despite the financial struggles and limitations, there are positives to come out of these situations. Parents noted that the growth of their child makes the negative financial issues worth the struggle. This notion is supported by the research conducted by Rice and Belin...
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(2009) and Carbone, Behl, Azor & Murphy (2010), showing the possible motivation driving parents to continue their role as care coordinator for their child. Growth can help a child with ASD to reach their fullest potential, as was the case with one of the participants in this study, who, because of the care and treatments she received was able to obtain her college degree, obtain a job and reach a high level of independence.

The possible applications for this research include, but are not limited to, the following, which also intertwine with the three mentioned themes of this study’s results. The first possible application is to provide more effective care and funds for individuals with ASD. With the responses from parents of children with ASD, and a better understanding of the struggles, limitations, and positive aspects involved with the financial cost of ASD, an effective approach to provide needed care and funds for these children can be reached. Many of the financial issues with the cost of ASD, as seen with this study, center on health care providers. The role these providers play in the coverage of care and treatments leads to the second possible application for this study; to bridge gaps between Healthcare providers and parents (Carbone, Behl, Azor & Murphy, 2010). By filling in this gap, better care and services can be provided for children with ASD and their families. The third possible application for this study is, increased support and information for parents. With the parental perspective, this study seeks to utilize their responses as fuel for future research of this nature, as well as to increase the resources available for parents. The large financial cost of ASD is an issue parents of children with ASD, health care providers and society must face, thus it is important to understand the many different aspects of these cost and the affect they have on those paying for the care and treatment of ASD.
References


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adxnni=1&ref=health&

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http://www.nichd.nih.gov/health/topics/asd.cfm

Appendix 1

Dear _______________,

My name is Sharon Turnbow and I am a senior psychology major at Hanover College in Southern Indiana. I am currently looking for participants to assist me with my senior thesis on the financial factors associated with Autism Spectrum Disorder. With this research I hope to add to the growing study of Autism Spectrum Disorder and to further the interest and information on the topic.

If you could pass the following survey along to parents who have a child with ADS, I will be more than willing to share my findings and final report with you.

http://psych2.hanover.edu/research/SeniorProjects/2012/turnbrow/

Thank you for your support and aid in furthering ASD research.

Sincerely,

Sharon Turnbow

Senior Psychology Major

Hanover College

turnbows12@hanover.edu
Consent Form

This research is being conducted by Sharon Turnbow, a senior psychology major at Hanover College. This study seeks to better understand how financial factors (related to Medicaid and insurance) have impacted the care and treatment of children with Autism Spectrum Disorder from the parents’ perspective. You will be filling out a survey as well as demographics form.

This information will be used in a senior research project that will start in January of 2012. The survey you will be filling out seeks to understand how financial factors have impacted the care and treatment of children with Autism Spectrum Disorders.

The entire survey and demographics will take no longer than 15 minutes. There are no known risks involved in being in this study, beyond those of everyday life. The information you provide during the survey is completely anonymous and at no time will your name be associated with the responses you give.

If you have any questions or concerns now or after the study, please contact:

For questions about the research itself, you may contact the researcher: Sharon Turnbow at turnbows12@hanover.edu.

For questions about your rights as a participant in this research, you may contact the faulty member supervising the research Dr. Stephen Dine Young, a member of the Hanover Psychology Department as well as a licensed clinical Psychologist.
(youngst@hanover.edu, (812) 866-7319). You may also contact the chair of Hanover College’s Institutional Review Board, Dr. Bill Altermatt, at altermattw@hanover.edu.

Participation in this survey is voluntary. Refusing to participate or ceasing to participate at any time will involve no penalty.

By clicking here I agree to participate in this study

The impact of financial issues on care of children with ASD: A Parental Perspective.

Demographics

• Your Age (parent)

• Age of child with ASD

• Gender of Child
  o Male
  o Female

• Which best describes the area you live in?
  o Rural
  o Suburban
  o Urban

• Marital Status
  o Single
  o Married
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- Divorced or Separated
- Spouse Deceased

- How many children live at home

ASD History

- At what age did you first notice signs of ASD in your child?
- At what age was your child first diagnosed with ASD?
- Estimate your child's level of functioning
  - Low
  - Moderate
  - High

- What is your child's diagnosis?
  - Autism
  - Asperger Syndrome
  - PDD-NOS
  - Other
    - If other please specify

Past and Present Services

- What resources have you found to be the valuable in finding information about ASD? (Mark all that apply)
  - Medical Professionals
• Behavioral Professionals

• School System

• Other parents of children with ASD

• Web resources

• Support groups

• Other

  ▪ If other please specify

• What treatment approaches (For example behavioral, diet, medications, etc.) have you found most useful for your child? (Please Describe)

**Funding of Services**

• What is your best estimated percent of how your child’s health care cost are covered

  o Public health care providers (Medicaid, State funded programs and other government funded programs.) _____%

  o Private Insurance _____%

  o Personal funds _____%
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- Other (please specify)

- Do you feel that all of the necessary needs of your child with ASD are covered by your health care provider?
  - Yes
  - No

  - If no, what areas of treatment and care are lacking coverage? (ie. What additional treatments would you add if money were not an issue?)

**Impact of Finances**

- Please describe how finances affected care and treatment your child (both in a positive and negative way).

- If a family has recently had a child diagnosed with ASD, what resources and/or advice would you provide them with?

**Debriefing Form**

This study seeks to better understand how financial factors (related to Medicaid and insurance) have impacted the care and treatment of children with Autism Spectrum Disorder from the parents’ perspective.

If you have any questions or concerns now or after the study, please contact:
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Appendix 3

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3/19/12 lisa_fox@comcast.net National Autism Association of
fongfam5@att.net Northwest Indiana
Arkansas

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kmackrosenberg@gmail.com  National Autism Association of New York Metro

donnieapattison@yahoo.com  National Autism Association of North East Ohio

sammycoonis32@yahoo.com  National Autism Association of Southeast Ohio

nagla_alvin@verizon.net  National Autism Association of North Texas

jklocke5@msn.com  National Autism Association of Western Utah

Autism Society of America - Oakland County Chapter

SE-WCC@comcast.net  Autism Society of America - Southeast Wayne County Chapter

kalbc@asa-kal.org  Autism Society of Kalamazoo/Battle Creek

Michigan@autismsocietyofamerica.org  Autism Society of Michigan

asws_contact@yahoo.com  Autism Society of West Shore

Macomb/Saint Clair Chapter - Autism Society of America

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rica.org

mi-

wayne@autismsocietyofamerica.org

Wayne County Chapter - Autism

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Advanced Pediatric Therapies

info@arawa.org

Arc of Washington State

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Asperger Support Network

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Autism Resource Center

julie@autismpathways.com

AutismPathways

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Family Support Network of

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Lewis County

Bemorapath

tonya.kellerman@goodsamhealth.org

Therapy Unit

christineb@childrensdc.org

Parent Support Group for

Children with Autism

Parent to Parent Power

yyone_link@yahoo.com

Community Parent Resource

info@psaasa.org

Center

Puget Sound Autism Aspergers

support@psaasa.org

Support Associates

Sibshop

bathy.harrison@seattlechildrens.org

Children's Hospital and Regional

Medical Center

Sibshop

alixk@pugetsoundtherapyservices.com

Puget Sound Therapy Services

Sibshop

krisk@arcofclarkcounty.org

Arc of Clark County
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<td>Program Young Adult Social Group</td>
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Appendix 4

Public

• Financial Effects

  o Positive

  ▪ P1-If not for state medical I would not be able to seek help at all.

  ▪ P6- Medicaid will pay for any medication or test

  ▪ P9- After fighting for two years he now has a Level 1 waiver, which comes with an Ohio Medical card so now all his therapies are paid for.

  ▪ P10- Medicaid has been a blessing. Medicaid has covered most of the therapies and diagnostic testing.

  ▪ P10- The NAA-SEO has also been very helpful in providing a grant to explore biomedical treatment options
- P19- 10-12 years down the road he will be able to get Music Therapy if he's on the Waiver at that point.

- P27- He is able to receive routine care from his pediatrician and Psychiatrist.

  - Negative

- P1- My daughter’s health care costs are astronomical

- P2- When he could not get insurance he couldn't even go to the psychologist because we have no money for doctors or specialists

- P6- There are many things that I would try with my son but finances prevent it

- P6-When it comes to preventative care or supplements rather than meds there is no help.

- P9- Private health insurance would not pay for any of his therapies as it was considered Mental Health.

- P9-We made too much money to qualify for a medical card through Social Security.

- P9- We paid out of pocket for all therapies.

- P10- our health insurance does not cover anything related to autism or developmental delays.
THE ECONOMIC IMPACT OF ASD

- P14- I think that if we had more money we would be doing more sensory techniques with him. Those sensory items are very expensive so we have taken to trying to duplicate the items in a more cost effective fashion.

- P19- We feel that there are things that could benefit our child but we can't afford them and Medicaid does not cover most of them. Like Music Therapy.

- P21- I can't work because of autism dx which means immediately the income level in our house is less than half what it was

- P21- We cannot get ABA without some type of insurance.

- P24- It's hard to have gas money to get to the m-f appts.

- P27- Due to lack of experience with autism within our healthcare industry we must travel to Children's hospital over an hour away for routine dental procedures.

- Personal Effects
  - Positive
  - Negative

- P1- When I am fighting with the state about the costs she withdraws into herself because she feels my frustration.
- P2- He has been unable to find a job and unable to finish college.

- P10- It has been very stressful on our family though trying to find these resources and get everything in place and also buying all of the special items/foods that our son needs.

- P21- It breaks our heart that child is not going to have a very good prognosis long term and probably will be on public assistance for her entire life.

Private Insurance

- Financial Effects
  - Positive
    - P4- The Episcopal diocese which runs St.Luke's gave us financial assistance from the hospital's foundation to pay part of her hospital bill
    - P4- Through the kindness of strangers and our own assets we were able to pay for the therapy that changed her future
    - P7- We were lucky in that we had family willing to contribute to the cost of his care
    - P17- No effect.
  - Negative
THE ECONOMIC IMPACT OF ASD

- P3- We feel limited to where we can go for summer school help. Places are very expensive and private insurance is picky about they will cover.

- P3- We do not qualify for any State funded programs

- P4-When she was a preschooler and an outpatient at St. Luke's Hospital's Children's SPOT (speech physical occupational therapy) the bills were crushing

- P4-We cashed out all our savings and investments and sold jewelry and silver flatware. It took five years to dig out of debt from this episode.

- P7- Co-pays and deductibles were higher for things he needed like occupational therapy.

- P13- If finances were unlimited I would privately pay for dyslexia testing for my son. I would also send him to additional activities to allow him to learn social skills.

- P15- We carry a large credit card debt due to the treatments that we done.

- P20- Low funds for the family means not very reliable transportation. Not to mention the high gas prices!

- P23- Care for our child is very expensive when we need respite. $12-$14/hour
- P23- Mom has given up her career to take care of child $60 000 salary.

- P25- My husband's income makes him ineligible for any of the State programs like SSI or Voc-Rehab.

- P25- He has no transportation except for us because we cannot afford to pay for private transportation and he is not on a bus route.

- P25- We make too much money for any help at all.

- P25- His medical care covers the medical part of things but not any of the job skills/psychosocial side of things.

- P26- Proofing our home for him has been somewhat expensive. Special locks for doors and windows can become expensive very quickly.

- P28- We worked for 18 months to reach a point where we could afford ABA therapy...we still can't without government assistance.

- P29- Military insurance is nice to have unless your child is affected by autism.

- Personal Effects
  - Positive
    - P4- Today she is a community college graduate who holds a medical coding certificate and works full time as a billing assistant
at a safety net clinic. She rides the city bus system independently
to work and to go on outings. She still lives at home with us but we
plan to get her into her own studio apartment in our building by the
time she is 30.

- P23- Finances to date have not affected the care or treatment of our child.

- P26- Proofing our home for him has been worth the peace of mind it provides us

  O Negative

  - P20- My child can't do as many things as others because we live in a rural area with no public transportation

  - P25- He is not eligible for any other programs because he is 'too high functioning'

  - P25- He cannot get a job and struggled in college without any supports.

  - P26-We rarely buy new things for ourselves focusing our efforts on better treatment and activities for him.

  - P28- We worked for 18 months to reach a point where we could afford ABA therapy...we still can't without government assistance. That was 18 months in which my son lost all of his vocabulary and became aggressive because of his inability to communicate. Now
our issues are not just with speech and social interaction. They contain head butting grinding teeth biting insomnia etc.

Personal Funds

- Financial Effects
  - Positive
    - P16- Luckily I make a good living and have never had to hesitate when considering care.
    - P18- Finances were not a barrier.
  - Negative
    - P5- I can't work because my son was not receiving services at school so I am homeschooling him; this hurts our finances.
    - P11- ABA is usually 40K to 80K per year and this was not within our means.
    - P12- We had to refinance our house in order to pay for medication hospital stays and respite care.
    - P16- His childcare for summers and after school has cost us 15000 to 18000 dollars a year
    - P22- In debt

- Personal Effects
THE ECONOMIC IMPACT OF ASD

- Positive
  - P5- His growth makes it [the sacrifices] worth it.
  - P22- Did not let lack of money keeps us from treatments

- Negative
  - P5- We have to make sacrifices (no vacations) so we can have money to pay for our son's services.
  - P18- Lack of services and unawareness of what was available were far more significant.