Sample Letters from Families to Employers

These resources are intended to help families approach their employers about adding benefits to their company health plan. We hope these materials help you convince your employer to offer meaningful autism benefits.

CONTACT:
advocacy@autismspeaks.org
Dear Ms. Nelson:

I write to request that Princeton University amend its self-funded health plan. Specifically, I request that Princeton implement autism benefits, including coverage for Applied Behavior Analysis (ABA), commensurate with the New Jersey autism insurance reform law passed on August 13, 2009.

Because autism is a severe, chronic developmental disorder, which results in significant lifelong disability, the goal of treatment is to promote the child’s social and language development and minimize behaviors that interfere with the child’s functioning and learning. Applied Behavior Analysis, or ABA, is a method of teaching children with autism. It is based on the premise that appropriate behavior – including speech, academics and life skills – can be taught using scientific principles. ABA assumes that children are more likely to repeat behaviors or responses that are rewarded (or "reinforced"), and they are less likely to continue behaviors that are not rewarded. Eventually, the reinforcement is reduced so that the child can learn without constant rewards.

ABA is considered by many researchers and clinicians to be the most effective evidence-based therapeutic approach demonstrated thus far for children with autism.1 Several landmark studies have shown that about 50% of children with autism who were treated with the ABA approach before the age of four had significant increases in IQ, verbal ability, and/or social functioning. Even those who did not show these dramatic improvements had significantly better improvement than matched children in the control groups. In addition, some children who received ABA therapy were eventually able to attend classes with their peers.2

The efficacy of ABA has been widely endorsed by medical and governmental authorities. The U.S. Surgeon General states: “Thirty years of research demonstrated the efficacy of applied behavioral methods in reducing inappropriate behavior and in increasing communication, learning, and appropriate social behavior.”3 The National Institute of Mental Health echoes this conclusion: “Among the many methods available for treatment and education of people with autism, applied behavior analysis (ABA)

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has become widely accepted as an effective treatment.”

In 2007 the American Academy of Pediatrics reported, “The effectiveness of ABA-based intervention in ASDs has been well documented through 5 decades of research by using single-subject methodology and in controlled studies of comprehensive early intensive behavioral intervention programs in university and community settings. Children who receive early intensive behavioral treatment have been shown to make substantial, sustained gains in IQ, language, academic performance, and adaptive behavior as well as some measures of social behavior, and their outcomes have been significantly better than those of children in control groups.”

In the past, insurers have denied coverage for ABA on the basis that it is “experimental.” But this claim is simply not supported by science, as evidenced by the research cited above. Recognition of the efficacy of ABA for improving the quality of life for children with autism has led states across the country to mandate state-based health insurers to cover evidence-based medically necessary autism therapies, such as ABA. Twenty-one states have now passed autism mandates. Twelve more states are currently considering them. On August 13, 2009 New Jersey became the fifteenth state to implement this reform, as Governor Jon Corzine signed the autism insurance reform bill, S. 1651/A. 2238, into law. The New Jersey bill requires insurers to cover up to $36,000 annually for a child with autism that is 21 years of age or younger. Coverage includes ABA therapy.

Although this law is not enforceable on self-funded health plans, such as Princeton’s, many companies and institutions are choosing to voluntarily comply with the provisions of state-based autism insurance reform. Companies such as Microsoft, Home Depot, Deloitte, Time Warner, Haliburton, and institutions of higher education such as Ohio State University and the University of Minnesota, have opted to provide coverage for autism therapies within their own self-funded health plans.

In fact, it may be only a matter of time before self-funded health plans are mandated to cover ABA and related treatments. The “Autism Treatment Acceleration Act of 2009” (ATAA), currently being considered by Congress, provides for federal reform of autism insurance coverage. If passed, the ATAA will require all insurance companies across the country to provide coverage for evidence-based, medically-necessary autism treatments and therapies. If passed, this federal bill will supersede all state laws and become the “floor” requirement for all insurance companies, including fully-funded and self-funded individual and group health plans.

Princeton should cover ABA for employee dependents with autism as part of its mission to be a family-friendly employer. According to the Princeton University Human Resources website: “Princeton University cares deeply about providing a campus environment and a range of programs that assist faculty and staff in achieving an appropriate balance among work, personal and family commitments.” From stopping the tenure-clock, to subsidizing backup childcare to generous leave policies for new parents, Princeton strives to be a family-friendly place and advertises itself as such.

Beyond its place in Princeton’s mission, implementing autism benefits makes good financial sense for the University and for society. It behooves the University to help employees provide treatment for their autistic children. Employees whose autistic children can benefit from ABA will be more productive. Employee retention is maximized as faculty and staff will not feel the need to leave Princeton in search of

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6 http://www.princeton.edu/hr/benefits/worklife/
a job with state-regulated insurance. Autistic children who are helped by ABA to achieve higher levels of functioning have lower overall health costs and need less assistance from their families. Successful early intervention for children with autism significantly reduces the future burden on taxpayers. A Pennsylvania study of private insurance coverage for autism therapies projected an actual cost savings to that state of over a million dollars per child.7

Princeton University itself has a history of supporting the autism community generally and ABA programs specifically. This summer, the Woodrow Wilson School is holding a Junior Summer Institute on autism and domestic public policy. One of the speakers at this workshop is Lorri Unumb, Senior Policy Advisor and Legal Counsel to Autism Speaks, who will be promoting autism treatment coverage through health insurance. One of Princeton’s Community Based Learning Initiatives places Princeton students at Eden Institute, Inc., one of the premier ABA service providers in New Jersey. Indeed, Andy Armstrong, Director of Grants and Stewardship at Eden Autism Services Foundation, praises the long history of mutually beneficial collaboration between Eden and the University. University faculty and students maintain important connections with Eden: faculty members take classes there, students volunteer there, and student groups hold an annual fashion show fundraiser on Eden’s behalf.

For all of these reasons, I urge Princeton University to voluntarily implement autism benefits in its self-funded health plan. ABA is supported by science. It is well regarded in the medical community. Funding autism therapies, including ABA, is in accordance with Princeton’s family-friendly mission and its history of supporting the autism community. It is the right thing to do for the university, its employees, and the greater community.

Lorri Unumb of Autism Speaks has helped other institutions implement autism benefits in their self-funded health plans. She stands ready to help Princeton University take this step and can be contacted at lorri.unumb@autismspeaks.org.

On behalf of my son and all the other children of Princeton employees who are fighting against the limitations of autism every day, I thank you for considering this most urgent request.

Sincerely,

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RE: Ryan’s Law

Benefits for children with Autism

July 1, 2008

To (HR President),

My name is [Redacted]. I am a Physician Practice Specialist at the [Redacted] Medical Campus. I enjoy serving the community in my position and helping patients and their families experience the Planetree vision that the Greenville Hospital System supports. As their first contact, I strive to make every patient’s emotional, physical, and financial concerns my top priority. Every evening I come in to work, I remember that this is my primary goal.

My day job is raising my two children. [Redacted] is 5½ years old and [Redacted] is 3½. I love that job too! There are many similarities in nurturing their development to the ideals brought forth in the Planetree vision. I strive to make my children’s emotional, physical, and financial concerns a priority. This has become increasingly difficult as we try to pay for my son’s treatments for Autism.

A recent report by the federal Centers for Disease Control and Prevention shows that as many as one child in 120 is now diagnosed with an autism-type disorder. While doctors have been unable to explain the reasons behind this startling increase, research on how best to treat and teach autistic children has confirmed the value of an early intervention program that relies on intensive behavioral therapy. More than 500 medical studies published in the last two decades and the Surgeon General support the behavioral techniques, focused on teaching everything from language and academics, to basic life skills, help substantial numbers of preschool-age children with autism achieve intellectual, academic, communication, and social skills that approach normal range. (SmartMoney magazine, “Families Changed Microsoft’s View of Autism,” May 8, 2007)

The cost of Intensive Behavioral Therapy can be up to $50,000 per year. In comparison to other childhood diseases and their prevalence, the following chart shows the lack of funding for treatment of autism:

<table>
<thead>
<tr>
<th>Childhood Disease</th>
<th>Prevalence</th>
<th>Private Funding</th>
</tr>
</thead>
<tbody>
<tr>
<td>Leukemia</td>
<td>1 in 25,000</td>
<td>$310 million</td>
</tr>
<tr>
<td>Muscular Dystrophy</td>
<td>1 in 20,000</td>
<td>$175 million</td>
</tr>
<tr>
<td>Pediatric AIDS</td>
<td>1 in 8,000</td>
<td>$394 million</td>
</tr>
<tr>
<td>Juvenile Diabetes</td>
<td>1 in 500</td>
<td>$130 million</td>
</tr>
<tr>
<td>Autism</td>
<td>1 in 150</td>
<td>$15 million</td>
</tr>
</tbody>
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www.autismspeaks.org
To help the lack of funding, the State of South Carolina unanimously passed a law (Ryan’s Law) requiring insurance companies to recognize autism therapies, including those using behavioral training techniques, and to pay for such autism therapies consistent with the insurance coverages otherwise being offered for other physical illnesses under a heath insurance plan. That law goes into effect on July 1, 2008.

The recently passed Ryan’s Law does not apply to self-funded insurance entities, which is the purpose in writing this letter to you. I have talked to representatives at CIGNA Healthcare and they informed me that it is up to my employer to decide whether they would like to follow Ryan’s Law and give coverage to their employees with autistic children.

As one of your employees, I am hoping you will consider this proposal as a means of supporting your employees and providing partial relief to the financial burdens associated with raising an autistic child. My hope for my son is to help him develop and grow into an independent adult so that we will never have to put him in an institution. We love him so much and our hearts ache as we watch him struggle to speak and learn how to engage with others. We have seen the benefits of ABA Therapy and would love to be able to give our son the therapy he needs to progress towards being a typical child, the best he can.

A copy of Ryan’s Law is attached to this letter for your review.

I look forward to talking to you,
June 10, 2011

Tom Georgens  
Chief Executive Officer  
NetApp, Inc.  
495 East Java Drive  
Sunnyvale, CA 94089

Dear Mr. Georgens:

We are writing on behalf of several of your employees in response to a recent letter from Cigna Healthcare about pending changes to NetApp’s coverage of autism treatments. By way of background, Autism Speaks, which is North America’s largest autism science and advocacy organization, has successfully advocated across the country for insurance reform to cover behavioral treatments for autism. Several months ago, Autism Speaks assembled a workgroup to examine issues relating to insurance coverage for autism treatments among self-insured plans. The members of our workgroup have varied backgrounds, but most of us have family members with autism, and we have begun working together to help families obtain critically-needed treatments for their loved ones affected by this disease.

We applaud the leadership that NetApp demonstrated when it established an autism benefit for its employees in 2006. NetApp was on the leading edge of an emerging trend where today a majority of states across the country have laws requiring state-regulated health insurers to cover evidence-based autism therapies, such as Applied Behavior Analysis, or ABA.

Because autism is a severe, chronic neurological disorder, which can result in significant lifelong disability, the goal of treatment is to promote the child’s social and language development and minimize behaviors that interfere with the child’s functioning and learning. ABA is a method of treating children with autism. It is considered by many researchers and clinicians to be the most effective evidence-based therapeutic approach demonstrated thus far for children with autism.1

- The efficacy of ABA has been widely endorsed by medical and governmental authorities including the U.S. Surgeon General, the National Institute of Mental Health, and the American Academy of Pediatrics (AAP).
- The AAP noted that “The effectiveness of ABA-based intervention in ASDs has been well documented through 5 decades of research . . . . Children who receive early intensive behavioral treatment have been shown to make substantial, sustained gains in IQ, language,

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academic performance, and adaptive behavior as well as some measures of social behavior, and their outcomes have been significantly better than those of children in control groups.\textsuperscript{2}

- Reflecting this consensus in the medical community, Independent Medical Review (IMR) panels in California, which review Experimental/Investigational and Medical Necessity appeals, have overturned health plan and insurer denials of ABA 90\% (53/59) of the time since 2008.\textsuperscript{3}
- This trend in decisions has prompted the California Department of Insurance (CDI) to issue a notice of enforcement of IMR statutes which flags that “insurers’ denials of behavioral therapy such as Applied Behavioral Analysis have been overturned in IMR.” The CDI further notes that some of “the insurers’ denials - based on a contention that the therapy was experimental or investigational - were overturned because such treatment is now recognized as the standard of care for autism.” CIGNA’s denials of ABA on this basis have been overturned by the CDI on at least two separate occasions.\textsuperscript{4}
- More than half of the states have passed insurance reform requiring coverage of applied behavior analysis, and 21 more states are pursuing such legislation because ABA is widely recognized as the standard of care for autism.
- While CDI does not regulate NetApp’s policy, CDI’s statement and the CIGNA IMR overturns suggests CIGNA’s contention that ABA is experimental, which NetApp appears to be relying on, is out of date.

It was therefore surprising to learn that you would be “removing coverage for early intervention therapies, such as ABA, as they are still considered experimental.” This is not supported by the decades of research that have established substantial evidence of efficacy as noted above. For employees whose children are affected by autism, the proposed policy, which includes speech, occupational, and physical therapy, but excludes ABA, is like having coverage for treatment of cancer that excludes chemotherapy.

Beyond its place in your mission to create a healthy work environment that fosters the collaboration and creativity for which you are known, covering early intervention and ABA makes good financial sense for NetApp and for society. Employee productivity is maximized when children receive ABA and thereby achieve higher levels of functioning, have lower overall health costs, and need less assistance from their families. Recruitment and retention is helped, as people will not feel the need to leave in search of a job that provides comprehensive coverage. Considering the significant increase in autism incidence, chances are at some point you are likely to lose out on a desired candidate because you won’t provide an autism benefit for his/her family member. You may not be aware, but since NetApp showed the leadership of starting the ABA benefit, a large list, including many of your peers, have added comprehensive autism benefits, including ABA. A sample of companies with such a benefit include: Analog Devices, Cisco Systems, Electronic Arts, EMC, Google, Intel, Juniper Networks, Microsoft, National Semiconductor, Oracle, Symantec (to be added July 2011), Wells Fargo, and Yahoo.

Successful early intervention for children with autism also benefits society by significantly reducing the future burden on taxpayers and contributing more individuals with autism into a productive work environment.

\textsuperscript{3} DMHC http://dmhc.ca.gov/dmhc_consumer/po/pc_imrdec.aspx
environment, further adding to the tax base of a community. A Pennsylvania study of state funding for autism therapies projected an actual cost savings to that state of over a million dollars per child.5

For all of these reasons, we respectfully recommend that you reconsider your decision to eliminate early intervention and ABA treatments. One of your employees recently met with Nancy Saunders, Senior VP of Human Resources, and provided her with a presentation which includes more detail on this information – a copy of that presentation is attached for your review. We would be happy to speak or meet with you directly; I can be reached at 803-582-9905. Also, two members of our workgroup are located in California and would be happy to meet with you: Kristin Jacobson, MBA, at (650) 759-5737 or kjacobson5@yahoo.com, or Karen Fessel, DrPH, at 510-325-0975 or karenfes@sbcglobal.net.

On behalf of your employees who are fighting the challenges of autism every day, we thank you for consideration.

Sincerely yours,

Lorri Shealy Unumb, J.D.
Senior Policy Advisor & Counsel
Autism Speaks

cc:
Nancy Saunders, Senior Vice President Human Resources, NetApp
Matt Fawcett, NetApp Plan Administrator, Senior Vice President General Counsel, NetApp

Attachments:
Family Presentation to Nancy Saunders, May 24, 2011

Dear [Director of Benefits],

I write to request that [Company Name] amend its self-funded health plan. Specifically, I request that [Company Name] implement autism benefits, including coverage for Applied Behavior Analysis (ABA), commensurate with the Massachusetts autism insurance reform signed into law on August 3, 2010.

Because autism is a severe, chronic neurological disorder, which results in significant lifelong disability, the goal of treatment is to promote the child’s social and language development and minimize behaviors that interfere with the child’s functioning and learning. Applied Behavior Analysis, or ABA, is a method of treating children with autism. It is considered by many researchers and clinicians to be the most effective evidence-based therapeutic approach demonstrated thus far for children with autism.1 The efficacy of ABA has been widely endorsed by medical and governmental authorities including the U.S. Surgeon General, the National Institute of Mental Health, and the American Academy of Pediatrics who noted that “Children who receive early intensive behavioral treatment have been shown to make substantial, sustained gains in IQ, language, academic performance, and adaptive behavior as well as some measures of social behavior, and their outcomes have been significantly better than those of children in control groups.”

In the past, insurers have denied coverage for ABA on the basis that it is “experimental” or “educational.” But these claims are simply not supported by science, as evidenced by the research cited above. Recently, the U.S. Office of Personnel Management (OPM), issued guidance to insurers who participate in the Federal Employees Health Benefit program stating, “The OPM Benefit Review Panel recently evaluated the status of Applied Behavior Analysis (ABA) for children with autism. Previously, ABA was considered to be an educational intervention and not covered under the FEHB Program. The Panel concluded that there is now sufficient evidence to categorize ABA as medical therapy.”

Recognition of the efficacy of ABA for improving the quality of life for children with autism has led states across the country to mandate state-based health insurers to cover evidence-based medically necessary autism therapies, such as ABA. Thirty one states, including Massachusetts have now passed autism mandates, requiring insurers to cover medically necessary treatment of autism, and specifically includes ABA therapy.

Although this law is not enforceable on self-funded health plans, such as [Company Name]’, many companies and institutions are choosing to voluntarily comply with the provisions of state-based autism insurance reform. Companies such as Microsoft, Intel, Home Depot, Deloitte, Time Warner, Comcast and

institutions of higher education such as Princeton, Ohio State University and the University of Minnesota, have opted to provide coverage for autism therapies within their own self-funded health plans.

Within Massachusetts, many self-funded corporations, including State Street Corporation and Partners Healthcare are covering services under the mandate. We believe a decision to cover treatment should be focused on need, but note that, according to the State’s independent analysis of the mandate, this coverage is not particularly expensive, and has a negligible impact on premiums. This is also supported by other financial analyses, and the experience in other states that already have similar laws. If this is of further interest we would be happy to put you in touch with people who could provide more specific details.

___________ should cover ABA for employee dependents with autism as part of its mission to be a family-friendly employer. According to the _________’s website: “__________ cares deeply about providing an environment and a range of programs that assist our employees in achieving an appropriate balance among work, personal and family commitments.” From subsidizing backup childcare to generous leave policies for new parents, _________ strives to be a family-friendly place and advertises itself as such. (look for similar statements/language on your company’s website/HR info).

Beyond its place in _________’s mission, implementing autism benefits makes good financial sense for the Company and for society. It behooves ______ to help employees provide treatment for their autistic children. Employees whose autistic children can benefit from ABA will be more productive. Employee recruitment and retention is maximized as people will not feel the need to leave _________ in search of a job with state-regulated insurance. Autistic children who are helped by ABA to achieve higher levels of functioning have lower overall health costs and need less assistance from their families. Successful early intervention for children with autism significantly reduces the future burden on taxpayers. A Pennsylvania study of private insurance coverage for autism therapies projected an actual cost savings to that state of over a million dollars per child.²

___________ itself has a history of supporting the autism community. (Note any past support for events, contributions, employee assistance with flexibility, leave-taking, etc. If there isn’t a lot of autism-specific things, you could cite support of families with other serious illnesses, disabilities, causes, etc.)

For all of these reasons, I urge _________ to voluntarily implement autism benefits in its self-funded health plan. ABA is supported by science. It is well regarded in the medical community. Funding autism therapies, including ABA, is in accordance with _________’s mission and its history of supporting the autism community. It is the right thing to do for _________, its employees, and the greater community.

The Autism Insurance Resource Center at UMass Medical School and Autism Speaks have helped other institutions implement autism benefits in their self-funded health plans. They stand ready to help _________ take this step and I would be happy to put you in touch with them directly.

On behalf of my son/daughter _______ and all the other children of _________ employees who are fighting the challenges of autism every day, I thank you for considering this most urgent request.

Sincerely,

Dear [company contact pronoun] [company contact last name],

I am writing on behalf of my [son or daughter], [name of child], who was diagnosed with autism in [month of child’s diagnosis] [year of child’s diagnosis]. As part of [name of child]’s treatment [child pronoun] has been prescribed applied behavior analysis (ABA). The health benefit plans offered by [company name] do not cover ABA for autism. This denial of coverage has created significant financial and emotional hardship for my family. I ask that you please consider adding coverage for ABA for autism to [company name]’s health benefit plan commensurate with [company state]’s autism insurance reform law which was enacted in [year AIR law enacted].

Autism is a neurological condition affecting brain development. While autism presents a spectrum of severity, all affected individuals share, to varying degrees, deficits in communication and social skills. Affected individuals also have repetitive patterns of behavior and a narrow range of interests. Although there is no cure for autism, it is treatable. Maladaptive behaviors can be eliminated and a child can develop appropriate communication and social skills.

ABA is a type of behavioral therapy and is the most commonly prescribed evidence-based treatment for autism. ABA is provided one on one and is very intense. Severely affected children may be prescribed as much as 40 hours a week for several years or more. Research demonstrates that almost 50% of children with autism that receive ABA will achieve a normal IQ. This compares to only 2% of children in control groups that did not receive ABA. Half of the children who receive ABA will mainstream in regular education without assistance by early elementary school. An additional 42% will improve such that they will require much less intense special education than if they had not received appropriate early intervention.

Forty-six (46) states require that state-regulated health plans cover the diagnosis and treatment of autism, including ABA. Actual claims data from States which were among the first to enact such legislation show the average cost of coverage is less than $0.50 per member per month. A growing number of self-funded health benefit plans also provide coverage for ABA for autism. A 2015 national survey of companies with greater than 500 employees shows that 37% of large companies (most of which provide self-funded health benefit plans) now provide health insurance that covers intensive behavioral therapies for autism such as ABA. In fact, 60% of companies in the Fortune 50 cover ABA, which includes two of the largest health insurance carriers. Autism claims data from these plans are consistent with that from state regulated plans, representing less than 0.2% of total health care costs.

While the costs of providing coverage for both state-regulated and self-funded health insurance plans has proven to be negligible, if forced to pay for treatment out of pocket the cost is prohibitive. Without the addition of a meaningful autism benefit to [company name]’s health plan that includes coverage for ABA, my family will not be able to provide [name of child] with this life-changing treatment.
Autism Speaks is the world’s leading autism science and advocacy organization. In addition to advocating for state autism insurance reform laws, Autism Speaks’ Government Affairs team also serve as a resource for companies that are considering adding an autism benefit to their self-funded health benefit plan. I have spoken to Lorri Unumb who is the Vice President, State Government Affairs at Autism Speaks and if you are available for a meeting she would be happy to discuss this with you and other representatives of the company in more detail. (You can reach her directly at lorri.unumb@autismspeaks.org.) Please provide me some possible meeting dates at your earliest convenience.

Thank you for considering making this change to the [Company Name]’s health plan, it that will be so important to my family’s future.

Since rely,

[Employee Name or Spouse]