

## Wellesley bus firm is autism group's Employer of Year

By Elana Zak/Townsmen staff

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Wellesley — When clients of the Wellesley-based Autism Services Association leave their shift at the Eastern Bus Company, they know they did more than simply clean a bus.

"It's been great for our people to have that work opportunity," said Joel Smith, ASA's executive director. "It gives them a lot of self confidence and a lot of self esteem. It makes them feel like a member of the community."

This year, ASA honored the Eastern Bus Company by naming it 2009 Employer of the Year. At the non-profit's annual meeting on May 6, it awarded the company, which is also based in Wellesley, with the title. They also honored their 2009 Worker of the Year, Emad Audy, and gave their 2009 Special Appreciation Award to Medford High School's student council.

"We were really happy to have that," Eastern Bus Company dispatcher and supervisor Magalie Marcelin said. "It was a surprise to us."

ASA started in 1963 to help serve the needs of individuals with autism and other developmental disabilities. The program aims to get young adults and adults with autism involved in the community, normally through a job. Working with people who don't have behavior or developmental problems allows ASA's members the ability to model that conduct and better communicate with others.

"When we see people working and making giant strides in terms of their own development, it's extremely satisfying," Smith said. "They model after so-called 'normal,' 'typical' people, and so their behaviors are better, they're more productive. They're able to use their potential better. They're able to contribute and be members of their community."

ASA first partnered with Eastern Bus Company in October 2006. In 2007, ASA workers began to work at the company's Waltham location. Today, there are workers at both the Wellesley Hills and Waltham locations. Out of 70 total members of ASA, five work with the Eastern Bus Company. The main task is to clean the buses, Smith said, something that they enjoy and makes them feel like they are back in school.

"Everybody's happy with their work," Marcelin said. "Everybody does a great job for us."

Audy, this year's worker of the year, has worked at a Shaw's Supermarket since March 2005, three years after joining ASA and learning a number of different job tasks. The West Roxbury resident works five days a week returning carriages to the front of the store. Rain or snow, Audy works hard at his job, Smith said.

"The mother had tears of joy," Smith said of Audy's mother at the ceremony. "It's a feel good kind of thing. It's a real recognizing thing. Everybody enjoys being recognized for achievement."

Medford High School junior Natalie Breen and Kevin Cullen, the school's student council advisor, represented the student council at the awards ceremony. The group helped raise \$420 for ASA. Breen's brother is autistic, which was one of the reasons the group picked ASA.

"It was a perfect fit for us," she told Smith. "I realize the importance of these programs."

The winners of the 2009 awards will be prominently placed on the group's Web site. Eastern Bus Company plans to continue working with ASA and was thrilled to receive the honor.

"I would like to say that it was really nice for them to come and work with us," Marcelin said. "They can do anything we do. It might take them longer to do it but they're still doing it and it's good to work with them."



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## About Us

The SAGE Crossing Foundation was begun in February, 2007, for the purpose of creating a green-model Massachusetts farmstead for autistic adults. SAGE was conceived as a template that can and should be reproduced on small farms and orchards throughout Massachusetts and the United States. The foundation was officially approved as a Massachusetts not-for-profit corporation on April 6, 2007, and received its Federal Tax-exemption as a 501(c)(3) organization on September 14, 2007.

Composed mostly of working mothers who have kept their young adult autistic children at home, the board of SAGE views the farmstead as a much-needed residential choice, supplementing traditional group homes and "shared living" models. Though there are many good group homes and placements in Massachusetts and elsewhere, with dedicated staff and beneficial activities, there are not nearly enough of them. Indeed, many group homes do not even accept autistic people. And not all autistic people can function well in these residential models.

Farms offer a quieter, safer environment for persons with autism; they allow many opportunities for exercise, and daily contact with animals. By making ours a green-model farmstead, with energy-saving structures; organic farming; nontoxic cleaners; and an environmentally friendly lifestyle that includes recycling, we will be setting a good example for the community. By building our farmstead on a small working orchard or farm, we will also be able to grow some of the farm's food, thus saving money while promoting a healthy lifestyle. And we will be preserving a farm – ultimately, we hope, a number of small farms and orchards – from development. (In Massachusetts, we now have only 6,000 farms –down from 11,000 fifty years ago.)

SAGE is conceived not as an island that isolates the disabled from the community, but as a bridge to the community: a place where people can purchase fresh produce, crafts and foods made at the farm; share recreational facilities; and attend fairs and other events. By placing a home, workspaces, and recreational facilities in the same location, we also believe that SAGE will be a more cost-effective model than traditional group homes, which require transportation to and from work or a day program.

## THE LOOMING CRISIS IN ADULT CARE FOR THE COGNITIVELY DISABLED

Many autistic people cannot get jobs in the community, or even do volunteer work – as many other disabled people do. They may make loud noises or behave in socially unacceptable ways. (Common behaviors include hand-flapping, head-slapping, and paper-shredding – even in public restrooms.) Some autistic adults need to be anesthetized for even routine medical and dental procedures. Even high-functioning persons with autism can require close supervision: they often frighten and annoy people with "inappropriate" questions and behaviors; they have limited awareness of danger. They cannot live or work in the community without a shadow.

Country life gives such people the room to be themselves and find their own way. Farm life, and the presence of animals, provides a therapeutic environment. Rural settings are safer for autistic people, who, even as adults, can bolt into traffic. Exercise – which calms the nervous system – becomes easy. Away from the terrors of the city, from the crowds and fluorescent lights that can make them more anxious, autistic people are better able to manage their strange behaviors and live productive lives.

And yet some government agencies regard farmsteads as a return to institutions. Now, when the vogue is "independent" living – which often translates into a group home or shared living (foster care for disabled adults), monitored more or less by staff – many disabled people and their strained, aging families, are left with unacceptable options. Some autistic adults end up on the streets, among the homeless population. Some remain at home, even as parents become ill.

Our philosophy, based on decades of experience raising our own autistic and cognitively disabled children, is that interdependency is best. Our most vulnerable citizens need people around for safety and comfort. But they also need a life that allows them to work with their strengths, and to be themselves.

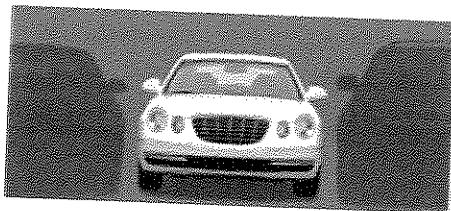
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12/3/09



## Thousands of local vehicles are just a click away!

Article published on April 07, 2009

### Prepare to care for a huge number of autistic adults

By Linda Davis The Washington Post

April 07, 2009

**Question:** What coming social expenditure will cost more than a third of this year's budget for the Department of Health and Human Services and be larger than the entire current budget of the Energy Department?

**Answer:** The bill for the tide of autistic children entering adulthood over the next 15 years, an estimated \$27 billion annually in current, non-inflation-adjusted dollars by the end of that period. The number of autistic children expected to need extensive adult services by 2023 - more than 380,000 people - is roughly equal to the population of Minneapolis. If a town were created to house this group of people and their caregivers - for you can't separate the two - it would exceed the population of all but six U.S. cities. If they formed a state, it would have four electoral votes.

But most of these cognitively impaired citizens don't vote. Most of them can't live alone or work in public places. Many can't even take public transportation by themselves.

Yet as World Autism Awareness Day passed this month, with the wrecking ball swinging at all levels of social services in this devastated economy, the challenges of adult autism continue to be overlooked. Many news reports focus on whether vaccines cause autism, the need for a cure or the education of autistic children. Autistic adults are relegated to the sidelines. Even the Obama administration, which has pledged better care for disabled Americans, including those with autism, has not been specific enough about its plans for those who will probably never be able to live independently or be part of the traditional workforce.

I understand that no one wants to look at a child and imagine the clunky, in-your-face adult he or she will become or think about the stares he or she will induce. When I look at my pudgy 22-year-old son, Randy, still sweet-faced but so obviously disabled, I cannot locate the blond cherub he used to be, gripping his stuffed brown bear. While writing this, I listened to Randy getting into the refrigerator (he's home again from his supervised job - two mornings a week - because of another problem with the overwhelmed human services provider funded by the Commonwealth of Massachusetts), and wonder who will love or at least protect him when he ends up in a group home run by an underpaid, overworked staff.

Randy's father and I are keeping him at home as long as possible, even as I'm battling an incurable cancer. The inadequate state services and perilously thin funding have seriously hampered our ability to work while caring for our son. I feel as though we're playing Russian roulette with Randy's future, yet I cling to my gentle son, unwilling to entrust him to a system that grows more fragile than I do.

Randy is just one of hundreds of thousands of autistic adults to whom society pays frighteningly little attention. The price of their care will affect all Americans, not only those who have autistic children. Along with housing, day programs, transportation to those programs or jobs, and higher-than-average medical costs, adults with autism require steady supervision and support.

Consider: A well-behaved, relatively high-functioning person such as my son could manage in an environment that has a ratio of three clients per staff member. But many autistic people require a one-to-one ratio. This is a serious hurdle, not least because of the high turnover rate among those who provide direct care, which stems in part from their low wages. Not everyone is temperamentally suited to this work. People with autism present myriad challenges: They can sometimes be violent, sometimes are self-abusive, suffer psychological meltdowns, or behave in many socially unacceptable ways, to say the least. Women, traditionally cast in the caregiver role, are at risk of greater physical harm when caring for autistic adults than for children. At expected rates, we will need to find an additional million caregivers, people who must have the right personal qualities to work with autistic individuals but who are unwilling and able to work for low wages. This is no small challenge. We not only must train people but also show that we value this work by paying them better.

In 15 years, the cost of care just for the autistic children entering adulthood over that time will be about equal to the current state budget of Tennessee. Meanwhile, services are dangerously strained, and the influx of autistic adults is under way. This country urgently needs to focus on adult autism, new models of care and new sources of funding. Before the looming tidal wave delivers another crushing blow to our economy, we should have a national discussion. It should begin today.

***(Linda H. Davis is the author, most recently, of Charles Addams: A Cartoonist's Life and is president of the nonprofit SAGE Crossing Foundation, formed to create a farmstead for autistic adults. Her husband, Chuck Yanikoski, who is treasurer of SAGE, contributed to this piece.)***

This article is: 240 days old.

12/3/09

## Record Number Of Researchers, Advocates, Parents Drawn To Autism Consortium Symposium For Autism Update

06 Nov 2009

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The Autism Consortium, an innovative collaboration of researchers, clinicians, funders and families dedicated to catalyzing research and enhancing clinical care for autism spectrum disorders (ASDs), held its fourth annual symposium on October 28th, 2009, at Harvard Medical School in Boston. The meeting gave scientists, clinicians, advocates and parents an opportunity to gather for the latest information on causes of autism and their implications for diagnosis, prognosis and therapies for people with autism spectrum disorders.

"We're proud to host this important meeting and facilitate what has become a unique and growing collaboration among scientists and families," said Peter Barrett, partner in the Life Sciences group at Atlas Venture and chair of the Autism Consortium's board of directors. "The symposium provides a forum for researchers working to find the next breakthroughs in autism to meet not only with each other to share their latest finding but also directly with practitioners who are treating children and their parents."

The symposium's scope and attendance doubled this year, with an increase in scientific posters presented from 19 in 2008 to 38 and attendance rising from 200 to 400 over last year.

"The dramatic growth of this year's symposium strengthens our resolve to bring researchers, clinicians and families together to move the needle on autism research as quickly as possible," said Deirdre Phillips, executive director of the Autism Consortium. "The Autism Consortium encourages families to become vested partners in the research process, participating in studies whenever they can to provide the broadest possible foundation for new discoveries that will lead to new treatments."

### Current Autism Issues Discussed

The symposium opened with a welcome from Barrett and Phillips. The morning session provided a snapshot of current autism issues:

- Laurie Demmer, MD, MA, chief of the division of genetics and metabolism at The Floating Hospital for Children at Tufts Medical Center gave an overview of the genetic changes that have been identified in children with autism. She also discussed a new study demonstrating the utility of clinical genetic testing in the diagnosis and treatment of children with ASDs.
- Representative Barbara L'Italien (MA), vice chair of the House Committee on Ways and Means, discussed new legislation that, if enacted, will mandate insurance coverage for diagnosis and treatment of ASDs.
- Susan Wilczynski, PhD, BCBA, executive director of the National Autism Center, discussed a study evaluating the effectiveness of autism treatments based on research study results published in peer-reviewed journals.

### Latest Autism Research Presented for Discussion

Throughout the day, 38 researchers presented posters on their ongoing research in autism, ranging from new advances in clinical care to data mining, RNA editing and genomic arrangements.

The afternoon session, lead by Mriganka Sur, PhD, Newton Professor of Neuroscience, Head, Department of Brain and Cognitive Sciences at MIT, included presentations on several promising areas of autism research and panel discussions among the presenters.

### Chromosome 16p11.2 and Autism

Autism Consortium research last year resulted in a study published in the New England Journal of Medicine showing strong and compelling evidence that a region on chromosome 16 appears to play an important role in susceptibility for autism spectrum disorders. Scanning genetic data from more than 3,000 individuals, researchers found that a deletion or duplication of a specific section of chromosome 16 (referred to as 16p11.2) accounts for approximately 1% of autism cases.

Since this discovery, researchers from eleven labs have begun an exciting collaboration on the investigation of this region of chromosome 16 and the role it plays in autism. Eight scientists working in this area presented an update on their latest findings:

- Mark Daly, PhD, Associate Professor, Department of Medicine, Massachusetts General Hospital, Harvard Medical School, and Senior Associate Member of the Broad Institute, presented continued genetics analysis of the 25 genes in the 16p11.2 region.
- Three investigators from Children's Hospital Boston presented their research on the human phenotypes associated with a deletion or duplication at 16p11.2.

David Miller, MD, PhD, Instructor, Department of Pediatrics, Harvard Medical School Division of Genetics and Assistant Director, DNA Diagnostics Laboratory, Children's Hospital Boston

Ellen Hanson, PhD, Instructor, Department of Psychology, Harvard Medical School and Developmental Medical Center, Children's Hospital Boston

Magdi Sobeih, MD, PhD, Instructor, Department of Neurology, Harvard Medical School and Department of Neurology, Children's Hospital Boston

- Three researchers presented work on understanding the role the 25 genes in the 16p11.2 region play in the mechanisms of neuronal development and brain formation in model organisms.

Mustafa Sahin, MD, PhD, Director, Multi-Disciplinary Tuberous Sclerosis Program and Department of Neurology, Children's Hospital Boston

Froylan Calderon de Anda, PhD, Postdoctoral Fellow, Tsai Laboratory, MIT

Damon Page, PhD, Postdoctoral Fellow, Sur Laboratory, MIT

Hazel Sive, PhD, Member, Whitehead Institute and Professor, Department of Biology, MIT, presented her work using the zebrafish as a tool to define the function of the genes contained in the 16p11.2 interval during early brain development.

### **Family Resource Fair**

For the first time in 2009, the Symposium included a Family Resource Fair, a forum for support and advocacy organizations to provide information on their programs and services. The Resource Fair was especially well received by the many autism family members and caregivers in attendance.

- Autism Consortium Autism Resource Specialists and Family Recruitment Network
- Family Autism Center, South Norfolk County ARC
- Autism Alliance of MetroWest
- Autism Support Center
- Spotlight Program, North Shore ARC
- The Doug Flutie, Jr. Foundation for Autism
- SPEDWatch
- Mass Family TIES
- E.K. Shriver Center, UMass Medical School

- Asperger's Association of New England
- Antioch University New England, Center for Autism Spectrum Disorder Training
- TILL, Inc.
- Urban PRIDE

Source: Kathryn Morris  
Autism Consortium

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12/3/0

## Cape couple develop practical applications for iPhone

By Sarah Shemkus  
sshemkus@capecodonline.com  
August 18, 2009 2:00 AM

MARSTONS MILLS — Around the time Graham Johnson turned 2, his parents Lisa and Jeff began to suspect that he was having developmental delays and anxiety problems. The year that followed was full of appointments with specialists and conversations with the school district about appropriate placement for Graham.

But now, the Johnsons have turned their yearlong struggle into a budding business, developing and selling iPhone applications intended to help autistic and developmentally delayed children. "We thought, 'We know it can help, and we can do it. So let's do it,'" Lisa Johnson said. Lisa, a physical therapist, and Jeff, a software developer and iPhone enthusiast, sat down at their kitchen table and brainstormed.

One of the communication tools they had found most useful in working with their son was storyboards — using a series of pictures to explain plans or ask questions. The technique is often used with children who have trouble either speaking or understanding verbal language. Storyboards typically use drawings, or a series of printed pictures that can be attached to pages with Velcro and carried in a binder.

A drive to school, for example, could be represented by a picture of the child, followed by an image of the car and then a picture of a school. When (Graham) could see a picture and know what was going to happen, he was much less anxious and better behaved," his mother said.

The Johnsons founded Grembe iPhone Apps — the company is named for Graham and his siblings, Emma and Ben — and created iCommunicate, an application that allows parents to create and store storyboards on iPhone or iPod Touch.

"I focused on what we used it for," Jeff Johnson said. The program can also be used to set up choices for children; rather than having to say out loud what he or she like for a snack, the child can select from a picture of pretzels and one of an apple. The application provides the same benefits as traditional storyboards, but is far more compact and discreet, means an already self-conscious child won't need to call attention to himself by toting around a bulky sheaf of papers, Lisa Johnson said.

"I love it," said Regina McClellan, a Scituate mother with a two year old autistic child. "I love it." She is preparing her son, Andrew, for their regular weekend trips to her parents' house in Chatham, she has a storyboard that includes his own picture, a shot of the car and an image of his grandparents. "I love it," she said. "I love it."

iCommunicate was released in early July, the Johnsons also launched iReward, which tracks how many actions a child must perform before earning a reward. The exact image and number of stars are set by the user.



are filled in; when they are completed, the reward is achieved.

Both programs come with hundreds of stock pictures representing common actions, objects and places. But users can also add their own pictures using the device's camera, which makes the storyboards even more effective, said Melanie Johnson, director of speech services at South Shore Therapies in Weymouth, who is just beginning to use iCommunicate in her practice.

"You have pictures of their house and their car and their school," she said. "It makes it much more functional for a child, less abstract."

The use of technology could have other advantages too.

Many children on the autistic spectrum are uncomfortable with interpersonal interactions and have trouble making eye contact.

"If the children have difficulty understanding social cues and context and feel uncomfortable with it, the delivery of a star or token on a electronic device may in fact produce better learning in some circumstances," said Dr. Dennis Russo, chief clinical officer with the May Institute in Randolph.

In fact, the use of iPods and similar technology to work with children on the autistic spectrum is increasing in popularity, he said.

"The opportunity to use technology to help teach is something that is widely being done in the field," Russo said.

Though it was their son's special needs that encouraged them, the Johnsons emphasized that the two applications can be useful tools for all children. They use them with Graham, as well as with Emma, 5, and Ben, 1.

"We just added some features that make it more useful for kids with special needs," Lisa Johnson said.

To market the applications, the couple has depended largely on Twitter and Facebook, where they have gotten "amazing" response, Lisa Johnson said.

And early satisfied customers are starting to spread the word.

Austin lets the families she works with know about iCommunicate, and they, in turn, pass the information on.

"I tell everybody about it," said McClellan, who originally heard of the program from Austin.

Looking ahead, the Johnsons plan to refine and upgrade the two applications.

Based on feedback from customers, Jeff Johnson has already started working on elements that would make iCommunicate more useful for teachers or others using the program with multiple children.

And his wife is thinking about pursuing grant opportunities that would allow them to distribute iPhones or iPod Touches to special needs classrooms.

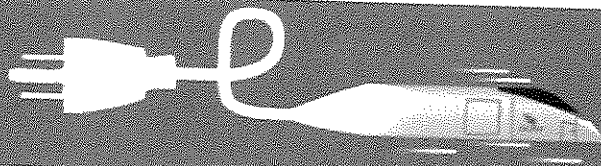
But given how unpredictable the process has been thus far, they are hesitant to say with any certainty what will come next.

"It's already gone in directions I didn't know it would go," said Lisa Johnson.

Added her husband, "It's been a pretty crazy month."

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## THE INDEPENDENT

May 31, 2009

### Better, faster... and no office politics: the company with the autistic specialists

*A pioneering company in Denmark is giving people with autism the chance to apply their skills to jobs from IT to product testing. The result is a huge success that's about to be rolled out across Europe. Founder Thorkil Sonne tells Michael Booth how his workforce's superhuman recall and unflinching focus could teach the rest of us a thing or two*

Thorkil Sonne and his wife already had two sons when their third, Lars, arrived in 1997, so they had plenty of experience of the behavioural quirks of growing youngsters. But as Lars entered kindergarten aged two-and-a-half, the couple began to notice a more troubling change. Lars wouldn't play with the other children, preferring to sit alone for hours on end. He began to talk less and less, until he was virtually unable to engage in any kind of dialogue at all. Something was clearly very wrong.

"We were patient," says Sonne. "Our older boys had taught us that each child has their pace at which they climb the ladder, but Lars seemed to be stuck on a step." The Sonnes are Danes and, fortunately, the Danish education system is good at diagnosing childhood developmental problems. Unfortunately in Lars's case, the diagnosis was childhood autism.

"It was scary. The first phase was denial: 'I've known my child for three years, you've only met him for two months. Don't come and tell me he has an incurable, life-long disability!' Then you have a bad conscience; you remember the situations where you've tried to use traditional means of raising kids and they didn't work. But it didn't take long, reading the literature, to realise it was describing Lars to the letter and, after time, we realised that Lars was still our happy, caring boy; we just had to get to learn about his world."

Most parents, upon learning their child has a condition like this, will read up on it, learn about the treatments, therapies and consequences and start planning for the future. Sonne went somewhat further. He became involved with his local autistic society, ending up as vice-chairman of a housing facility for people with Asperger's syndrome, a type of autism that affects social imagination, interaction and communication. Through the housing association, he got to know an 18-year-old Asperger's sufferer who was especially gifted with computers. "He had retired on a state pension," says Sonne. "But I thought that was so unfair as he had valuable IT skills that I could see would be useful for software- testing, support monitoring, programming and so on."

So, in 2004, Sonne left his job of 15 years at the Danish communications company TDC, remortgaged his house, and founded a company, Specialisterne (The Specialists), to find employment for adults with autism and Asperger's as software and systems testers. The 18-year-old Sonne had met through the housing association was his first employee.

Five years on, Specialisterne employs 60 people, has a turnover of almost £2m, and works with Microsoft (it tested Windows XP Media Center) and CSC, among other major international companies, helping them to check information systems, databases and other highly demanding, often repetitive, number-crunching tasks. Specialisterne has won numerous business and industry awards, and now has two offices in Denmark. If current plans pan out, a new branch will open in Glasgow later this year. It is a shining model of how to turn a highly skilled yet misunderstood and underexploited element of the population - around one per cent have a diagnosis of autism, but other related "invisible disabilities", such as ADHD (attention-deficit/hyperactivity disorder) for instance, may account for as much as 3.5 per cent of the population - into productive and integrated members of the workforce.

I am sitting with Sonne, a quietly spoken, rather studious man in his late forties, in his well-ordered office in a hi-tech industrial park on the outskirts of Copenhagen. As we talk about his son's condition, he plucks a piece of paper from a filing cabinet. It's a drawing his son made following a family holiday in southern Europe. I peer at the curious pyramidal temple of squares and numbers, trying to make sense of it. "It's Europe!" I realise after a few moments. "But what are the numbers?" Sonne produces a photocopy of the schematic contents page from his European road atlas, the atlas they used on the journey south. His son had reproduced it entirely from memory. "I've tried to find a single mistake, but I can't," Sonne says, still amazed by his son's memory.

It's a powerful illustration of the incredible, verging on superhuman, attention to detail, recall and unflinching 'focus' many autistic people have, whether expressed in architectural terms (as in Stephen Wiltshire's work - he can draw a landscape after seeing it once); linguistic (autistic author Daniel Tammet is said to have learnt Icelandic in a week); or, as is the case with many of Sonne's employees, numerical.

"There are so many different types of phones and services to be tested," Sonne explains. "And the work is very repetitive but requires full attention all the time. Most companies use students or outsource to India or wherever. The first couple of tests they'll do will be fine, but by the sixth, their attention wanes and it will always be the last test that's the most important." Aspergerians, on the other hand, relish the repetition, their focus doesn't waver and their numerical skills are superlative. "My staff are motivated all the time. Our fault rate was 0.5 per cent, compared with five per cent from other testers. That's an improvement by a factor of 10, which is why we can charge market rates. This is not cheap labour and it's not occupational therapy. We simply do a better job."

From the start, Sonne was clear that the company would operate under market conditions, and turn a profit, which made it virtually impossible to apply for government or EU support ("They just want people who will spend their money"). But, oblivious to the economic downturn, Specialisterne continues to pick up new clients largely by word of mouth. Organisations in more than 50 countries have approached Sonne to explore the idea of starting similar projects, with Norway and Switzerland likely to follow soon.

"I knew that the autistic people I met had dreams and ambitions, personalities and motivation," he continues. "The trick was to create an environment that supported them. If you think of a high wire, suspended between two buildings, you aren't going to take a chance and walk across it, even with a net. But if the wire was just a metre off the ground, you might try. It's the same with our company. We created stable ground for autistic people to walk on and I see them develop self confidence and open up to new things as a result."

Leading UK software-testing consultant Stephen Allott of ElectroMind has been acting as an unpaid adviser to Specialisterne as the company prepares to enter the UK market where, currently, only about six per cent of people with autism are in full-time employment. He is very clear on the advantages of using them: "Simply, they are better, faster and do higher-quality work than the people we can currently get from the labour market in the UK or India," he says. "One of their guys can read a technical document the size of a book and spot inconsistencies between something on page three and page 37, which is incredibly useful. I already have clients in the UK who are interested in what they have to offer. The only thing we need to be careful about is their working environment. I know lots of companies with noisy, chaotic, open-plan offices, where the work is like fire-fighting most of the time, and people from Specialisterne wouldn't be able to work there. That said, the environment they need is the kind of environment we should all be working in anyway."

Remarkably, about 70 per cent of Specialisterne's employees are stationed in client premises. I asked Sonne how easy it is for them to fit in with other working environments. "We create virtual Specialisterne environments in our clients' offices. Everyone who will be in contact with our consultants is briefed about the conditions they require. They have to be nice to our people, avoid stressing them. In Denmark, we use a lot of irony and sarcasm, but people with autism can't decode that. We make sure that the clients know how important it is to be direct, to outline tasks precisely and to stick to routines, particularly if any queries arise."

"That's how you avoid an 'I only fly with Qantas' freak-out?" I blurt. "Yes," says Sonne. "We've never had a 'freak-out'. In fact, saying what you mean, meaning what you say, being nice, avoiding stress are all good things in general for companies to take on board. Many have said to us that having one of our consultants has softened the atmosphere."

It must actually be a relief to work with colleagues for whom office politics, backbiting and bitchiness are anathema. "Yes, they are a happy and loyal group, no one ever talks badly about anyone else. It's nice to work with people who are honest, without filters. In fact I am working on a new management technique based on our experience with working conditions that are more open and direct."

This doesn't mean there aren't misunderstandings from time to time. "One of our consultants was working in an office where they introduced a free fruit basket. He went straight up and took a whole bunch of bananas back to his desk. Someone had to explain that it was expected to take perhaps one or two pieces of fruit a day, and then he got it."

It also doesn't mean that Specialisterne's workforce - 90 per cent of whom are male - are somehow robotic and unfeeling. "Oh no, in fact we have two employees who met at the company and are now engaged. Many socialise at the weekends and go out in Copenhagen together."

Sonne introduced me to one of his colleagues, Thomas Jacobsen, 27. Jacobsen's autism wasn't diagnosed until he was in his twenties and, meeting him, you can understand why. There is a slight social awkwardness (though probably little more than you would experience with anyone confronted by an inquisitive journalist), and nothing to alert you to the fact he has endured lengthy periods of depression in his life.

"I wouldn't say it was a relief, but it was nice to have a name for it, for my problem," he told me of his diagnosis. "Actually, I don't call it a problem, I call it a twist. Before, I felt I was different because I wasn't very social, I preferred being on my own and had lots of special interests: earthquakes, tsunamis, geography, GNPs..." GNPs? "Yes, you know, the gross national product of different countries. Since I started work here, I have learnt to cope better with social interaction,

I haven't had a depression in two-and-a-half years. I am getting more involved in bringing new ideas to the company and am part of shaping the Specialisterne Foundation [responsible for rolling out the concept to other countries]. You do have to have the right environment for people with Asperger's to function - there needs to be an acceptance that I am special, that I might not work regular hours, that I might have down periods - but if you have that in place, we can do any job."


Most Specialisterne employees tend to work 20- to 25-hour weeks, but Jacobsen has brought his hours up to 35. "You really blossom here. I see it with so many Aspergerians who join the company and get proper training. I have a lot of friends at the company now, and we socialise and go out together in town. We know we all have that twist."

I begin to wonder about all those other, less number-oriented skills that about 30 per cent of higher-achieving Asperger's sufferers display (to the extent that I rather wince to use the word "sufferer"). With a little lateral thinking, where else might fulfilling, productive roles be found for them in society? "Well, I would be very confident to know there were autistic people running air-traffic control towers," says Sonne. "In any company, at least one to five per cent of all tasks would fit well with the skills of people with autism. This could apply to recognition patterns in the medical industry, to accounting, to banks? Of course, some experts have identified autistic traits in people such as Mozart, Da Vinci, Newton, Einstein. If they were alive today, perhaps they would be recognised as having Asperger's, and look at what they achieved. Unfortunately, there is such an emphasis on being a team player and social skills in the workplace that there is still this resistance. But why do we all have to be like that? There should be room for other kinds of behaviour.

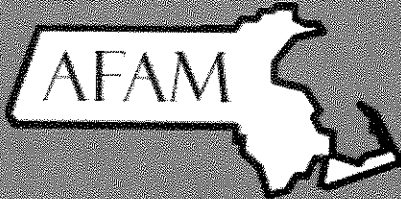
"My company is a showcase, but my end game is to get one million specialist people into meaningful work by providing a management model for large corporations to become attractive to people with special needs, so they know that they will be understood and supported. You know, in the UK you spend £12bn a year on the half-a-million Brits with autism. Why not get them earning that for the economy instead?"

Sonne's hopes for his son must have changed radically from that first diagnosis, nine years ago. "Well, he can work here, but only if he wants to. He's approaching some interesting times now as a teenager, but he is the nicest, most gentle and caring child you could imagine. It's a pity to think he might be bullied in society because of his way of being."

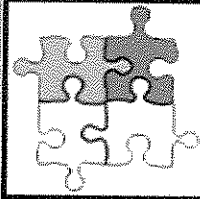
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12/13/09



# ADVOCATES FOR AUTISM OF MASSACHUSETTS



## AFAM BUDGETARY & LEGISLATIVE PRIORITIES

Advocates for Autism of Massachusetts (AFAM), the autism community's grassroots advocacy organization has designated its Budgetary and Legislative priorities for the coming fiscal year. AFAM will continue to advocate vigorously for the enactment of these priorities by our State legislature.

During the last five years, several of AFAM's legislative and budgetary priorities have been successfully enacted, including the establishment of the Division of Autism within the state of Massachusetts Department of Mental Retardation and the development of the Children's Autism Medicaid Waiver which provides intensive home based services to qualified children who are at risk of institutionalization. However, given the current economic climate, AFAM is very concerned about the impact expected budget cuts will have on the autism community. The 9C budget cuts implemented by Governor Patrick in October resulted in drastic reductions in vital services to children and adults with ASD. As the state develops a budget for the coming year, it is critical that families of children and adults with ASD tell their stories and share their concerns with their elected representatives. Let your state representative and your state senator know what programs and proposed legislation are important to you. After careful consideration and collaboration with stakeholders, AFAM has chosen the following budgetary and legislative priorities for the coming year.

## AFAM BUDGETARY PRIORITIES

### Level Funding for the Division of Autism (Including Children's Autism Medicaid Waiver) Line Item 5920-3010

The Division of Autism requires level funding to continue to provide services to the dramatically increasing number of children with ASD. Included in this line item is the Waiver program which provides low income young children with ASD at risk of institutionalization with intensive in-home services (ABA, Floor time and RTI). \$4 million is targeted to Waiver Services, an amount equal to the FY09 appropriation. The Commonwealth will be reimbursed 50% of the total costs of these services by the federal government. In addition to the Waiver, this line item also provides funding for programs offered to families by the Autism support centers. Level funding will enable the continuation of behavioral, social, and communication services and programs for children with ASD. AFAM seeks funding in the amount of approximately \$5.9 million for the Division of Autism.

### Level Funding for Family Support, DMR Line Item 5920-3000

The dramatic growth in the number of children with ASD is resulting in a greater demand for Family Support allocations. Thousands of families who receive family support use it to pay for respite and community programs for their children and young adults with autism. This program is a lifeline for many of these families. Elimination of funding for this program would be a tremendous hardship on families already facing difficult challenges. AFAM seeks level funding of approximately \$56 million for the Family Support Program.

### Level Funding for Turning 22, DMR Line Item 5920-5000

There has been a dramatic increase in young people with severe disabilities "Turning 22" and moving from the locally funded school programs into the state funded DMR system each year. It is thought that the rising rates of autism are contributing to this increased need. Funding for this vital transition program should not be reduced. AFAM seeks level funding of approximately \$7.7 million for the Turning 22 Program.

### Level Funding for DESE/DMR Collaboration, Line Item 5948-0012

DESE/DMR funding enables families with children with severe disabilities requiring intensive supports to continue to live at home and avoid costly residential placements. Many of the children who receive these services have ASD. There is a two year waiting list for this cost-effective program. During the first round of cuts by Governor Patrick in October, \$3.5 million in funding was eliminated from the program. Every family enrolled in the program saw their funding significantly reduced. Funding restored to last year's appropriation of \$10 million would reduce the wait list and ensure that more children with ASD remain at home with their families.

### Level Funding for Day/Employment Services, Line Item 5920-2025

As the number of adults diagnosed with ASD continues to climb, employment services critical to help these adults remain employed, particularly in this economic downturn must be maintained. Absent these supports, jobs will be lost. For those adults with ASD unable to work,

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structured day programs with proper supports enable them to gain skills and remain in the community. Any reduction in funding would be a strain to older parents of adults with autism. AFAM seeks level funding of approximately \$129 million for the Day/Employment Services Program

## **AFAM LEGISLATIVE PRIORITIES**

### **An Act Relative to Insurance Coverage for Autism (H. 3809) Lead Sponsors: Rep. L'Italien, Sen. Berry**

This bill requires health insurers in Massachusetts to provide coverage for the diagnosis and treatment of Autism Spectrum Disorder, which currently affects 1 in every 150 children. It includes habilitative or rehabilitative care, pharmacy care, psychiatric care, psychological care and therapeutic care prescribed, provided, or ordered for an individual diagnosed with ASD by a licensed physician or a licensed psychologist who determines care to be medically necessary. Treatments include testing to diagnose autism, structured behavioral therapies including ABA, occupational therapy, physical therapy and speech therapy provided by certified or licensed providers. The proposed legislation does not limit the amount of coverage and has no age limit. To date, there are more than 110 co-sponsors of this legislation, representing a majority of the Massachusetts legislature.

### **An Act Relative to Improve Teacher Training in Augmentative and Alternative Communication (S. 223) Lead Sponsors: Sen. Creem, Rep. Bradley**

This bill will help to ensure that teachers receive training in augmentative and alternative communication methods necessary to educate children with disabilities who are nonverbal or who have limited speech. Thousands of children who are nonverbal or have limited speech (including children with ASD) rely on augmentative and alternative communication methods to interact with others, and many students are now being included in regular education. The bill directs the Board of Education to revise regulations for educator licensure so that all teachers are adequately prepared in methods of communication other than speech to facilitate interaction and inclusion and to ensure access to the general education curriculum.

### **An Act Addressing Bullying of Children with Autism Spectrum Disorder (H. 3804) Lead Sponsors: Rep. L'Italien, Sen. Jehlen**

This bill amends the Autism IEP Act to clarify that IEP Teams must address bullying of children with autism. Children on the autism spectrum are frequently victims of bullying, teasing, and harassment as a result of their disability. Children with Autism Spectrum Disorder (ASD) are especially vulnerable targets for bullying because they are sometimes viewed as atypical or "odd" by some of their peers, and are relatively defenseless. These children are unable to understand and protect themselves like other students due to the nature of ASD, which impacts communication, social, and behavioral skills. Because their disability deprives children with autism of the natural ability to understand signals, communicate and to protect themselves, these students require teaching, supports, and services to develop strategies to help deal with bullying. This bill ensures that these supports are provided, as appropriate, to address the needs of the individual child, through the IEP process.

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We urge you to participate in the process. Join us on April 28, 2009 at the State House for Autism Spectrum Awareness Day and help us to educate our legislators about these important budget and legislative priorities which, if adopted, will enhance the lives of people with ASD and their families.

Advocates for Autism of Massachusetts 4/15/09

[Click here](#) for a sample letter to send elected officials.

You also can support our advocacy by becoming a [member](#) of AFAM today. As an AFAM member you will receive periodic governmental updates and action alerts so you will be informed about critical issues affecting our families and can take action with your legislators.

**BECOME INVOLVED!**

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