

AAA

Adolescents & Adults with Autism A Study of Family Caregiving



Report #9 Study Update

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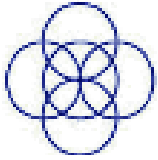
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Lifespan Family Research on Adolescents and Adults with Autism: A Study of Family Caregiving

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Greetings from the AAA study at the Waisman Center at the University of Wisconsin-Madison and Boston University. In this newsletter, we will provide you with updated information about the progress of our study, other research being conducted about autism at the Waisman Center, the Family Village, and what 2007 has in store as we continue to study the impacts of parenting an adolescent or adult with an autism spectrum disorder.

Study on Adolescents and Adults with Autism

From time to time, families ask us what we do with all of the information that we collect. Marsha Seltzer, Jan Greenberg, Gael Orsmond, and other researchers associated with the study present the results of our study at various scholarly conferences throughout the country and internationally. Also, since the inception of this study in 2000, twelve articles have been published in journals such as the *Journal of Autism and Developmental Disorders*, *American Journal on Mental Retardation*, and *Mental Retardation and Developmental Disabilities Research Reviews*. We currently have several other papers that have been accepted for publication and we are in the midst of writing more. By presenting at conferences and publishing our findings, we are able to offer valuable information which advances the fields understanding of autism during adolescence and adulthood and the clinical, educational, and support services for families of individuals with disabilities.

Our current focus is on the day-to-day stress experienced by families who have a son or daughter with an autism spectrum disorder living at home. Although there is now a growing understanding of how daily stress affects health and well-being in the general population, very little is known about how families with a child with autism cope on a daily basis with the stress they experience. The reason we are focusing this part of the study on families in which the individual with ASD lives with the parent is that we are interested in looking at the scope of "hands on" daily responsibilities and how stress affects caregivers during a 24 hour/7 day period of time. We know that stress does continue to occur even when a son or daughter does not reside with their parents, however we felt it was important to begin talking with co-residing families and expand our research from that point in the future. We

are very pleased that our study can be extended in this new direction, thanks to our new collaboration with Dr. David Almeida at Pennsylvania State University. The results will provide us with valuable data on the typical stressors that people living with an adolescent or adult with autism have to deal with in their daily lives and the toll this stress takes on their health and well-being. If you have a son or daughter living at home and have not yet been contacted, you will receive a mailing and phone call by March. Our hope is to have preliminary findings to share with all the families in our study by mid to late summer.

Finally, we are very pleased to share with you that our submitted application for the continuation of this study has been reviewed by the National Institutes of Health and we received very favorable feedback and scores. We are strongly committed to continuing our lifespan family research and visits with you to expand our understanding of the impact of autism on the family. There is also great importance in studying the life course of the sons and daughter with ASD. As an expert on your child, you possess knowledge and experiences which are incredibly valuable to us. We express our sincere gratitude for the time you take to talk to us on the phone, welcome us into your homes, complete questionnaires, and share the story of your life. Each visit moves us forward in understanding the impacts of parenting a child with ASD and we value your contribution to our research. We look forward to our next round of visits with you in the fall of 2007 as we continue our journey of learning together.

Other Autism Research at the Waisman Center

The Waisman Center continues to place a special emphasis on autism, including conducting cutting-edge research and providing quality clinical services to individuals and families. Researchers at Waisman are affiliated with 26 academic departments throughout the University. Due to the breadth of this expertise, many aspects of autism are studied, including the neurological, psychological, physiological, social, and genetic components. We would like to share a few as examples of the type of work being conducted.

Why the Increase in Autism?: Before the 1990s, autism was considered an extremely rare developmental disorder, affecting about 1 in every 2,500 children in this country. However, a little more than a decade later, the Centers for Disease Control and Prevention says that between 1 in 500 and 1 in every 166 children in the United States has autism. The question is, why? Waisman Center researcher **Maureen Durkin, Ph.D.**, also a member of the Department of Population Health Sciences is attempting to answer this question. Since 2004, she has been participating in a project funded by the Centers for Disease Control and Prevention

with the goal of establishing for the first time, an accurate count of the number of Wisconsin children and families affected by autism spectrum disorders, mental retardation or both. In addition, Dr. Durkin is examining the health needs of Wisconsin children with ASD, with the goal of increasing early detection of ASD and other developmental disabilities through specialized training of health care providers.

Twins and Autism: The very first population-based research on twins with autism is headed by Waisman Center researchers **Hill Goldsmith, Ph.D.** and **Morton Ann Gernsbacher, Ph.D.**, both also of the Department of Psychology. They study the importance of genetic factors as a cause of ASD. Drs. Goldsmith and Gernsbacher also study individuals who cannot use spoken language to communicate. Their preliminary findings indicate that early impairments in both manual and oral motor control are significant predictors of a child's overall level of speech. Dr. Gernsbacher is also teamed with Waisman Center researcher **Susan Ellis Weismer, Ph.D.**, also of the Department of Communicative Disorders, to investigate early communication and language in toddlers with ASD. Important findings from this study will help facilitate early diagnosis and effective language intervention programs.

Challenges in Communication: Discovering the causes of speech delays in young children is the focus of study for Waisman Center researcher **Larry Shriberg, Ph.D.**, of the Department of Communicative Disorders. The goals of his research are to understand the origins of such disorders and to develop assessment and treatment methods that help parents and professionals make the best clinical decisions for their children. Some examples of Shriberg's research include studies in the molecular genetics of speech disorder, speech disorders associated with middle ear disease, speech disorders within the autistic spectrum, and childhood apraxia of speech.

The Brain, Emotion, and Autism: **Richard J. Davidson, Ph.D.** of the Waisman Center, Department of Psychology and Department of Psychiatry, is conducting research using functional magnetic resonance imaging (fMRI) to study brain activity in relation to emotion in people with ASD. Results will provide a better understanding of brain differences associated with autism symptoms such as gaze aversion, anxiety, shyness, and social withdrawal. A recent article describing Dr. Davidson's work is included in this update.

Brain Imaging and Mapping in Autism: Waisman Center researcher **Andrew Alexander, Ph.D.**, also a member of the Departments of Medical Physics and Psychiatry, is studying brain structure and how the brains of children with ASD develop over time. This research has shown that brain structure correlates with clinical and behavioral measures of autism.

Social Interaction: Waisman Center researcher **Garet Lahvis, Ph.D.**, also of the Department of Surgery, is currently studying mice in order to increase understanding of the genetic bases of social behavior and challenges in humans. This research has the potential to provide insight into the genetic components of the social challenges associated with autism.

An Important Resource to Remember – The Waisman Center’s Family Village

The Family Village website (<http://www.familyvillage.wisc.edu>) is a global community that integrates information, resources, and communication opportunities on the Internet for persons with cognitive and other disabilities, for their families, and for those who provide families services and support. This internet-based community includes informational resources on specific diagnoses, adaptive products and technology, adaptive recreational activities, education, worship, health issues, disability-related media and literature, and much, much more!

At the online Family Village Library, one can browse topics ranging from general information about cognitive and developmental disabilities to the particulars of specific diagnoses, including ASD. The general information section offers support related to adults with disabilities, disability awareness, prenatal testing and diagnoses, siblings of persons with disabilities and self help or support groups. Also, there are suggestions concerning adaptive recreational activities for teachers and parents of people with disabilities.

The Family Village Coffee Shop allows visitors to make connections through discussion boards, chat rooms and traditional matching programs. Visitors can connect with people based on location or disability.

The Family Village School offers education related resources for families, teachers, and children. Parents gain a better understanding of how the educational system is set up to assist their child, as well as acquire support regarding having a disabled child in school. Teachers may find suggestions in planning effective lessons and efficiently incorporating disabled students into the classroom with other students.

The Living with a Disability “Just For Kids & Youth” link allows children to connect with other children with disabilities by interacting, sharing their own stories, and learning more about their disabilities. Information pertaining to disability-related legislation and civil rights, disability culture, and living with a disability, was recently added to the website.

The Waisman Center's online Family Village community provides many opportunities, information regarding specific diagnoses, support from others dealing with the same disabilities, and knowledge on how to live successfully with a disability or with a person with a disability. The goal is to offer you and others valuable, up-to-date, easy-to-access information!

Autism in the News

In addition to the article on Dr. Davidson's work, enclosed you will find an article from the November 27, 2006 issue of Newsweek entitled, **Growing Up with Autism**. We share this article with you because it complements the purpose of our lifespan research, which focuses on the transitions of adolescence to adulthood. It describes the unique challenges individuals with autism face as they try to successfully navigate in the world. The article also focuses on the question that thousands of parents of a child with a disability globally continue to ask, "what will happen to my son or daughter with autism when I die?" This question justifiably continues to be a concern as parents age and eventually are no longer able to provide the necessary daily care and support required by their child.

With the permission of the family in the second article, you will read about the journey of our study participants Robin and Landon Shipman. It has been a passion of this family to share their story of sacrifice and reward, and follow a dream. Among obstacles and hardships, Robin Shipman has been able to advocate for her son and for other individuals with autism in very creative ways. Robin's message to all families is to remain hopeful, positive, and keep reinforcing and sharing the unique gifts and qualities of your son or daughter.

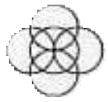
Comments, Questions, or Suggestions? We are always happy to hear from you!

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News & Noteworthy

Brain's 'fear center' may underlie autistic behaviors

by Jill Sakai
University Communications
December 12, 2006

The brain's emotional center is unusually small in autistic males with the most severe behavioral impairments, University of Wisconsin-Madison researchers reported this month.

The new study, appearing in the Dec. 4 Archives of General Psychiatry, represents the first direct link between the size of this brain structure, called the amygdala, and social deficits in autism, says [Richard Davidson](#), a UW-Madison professor of psychology and psychiatry and the senior author of the report.

The cause of autism, a developmental neurological disorder characterized by avoidance of social interactions and poor communication skills, is unknown, but several studies have focused on the amygdala, a small region of the brain involved in processing fear and emotions. Researchers believe a better understanding of the biology of autism will improve development of treatment methods.

People with autism have long been known to avoid making eye contact, even with pictures of faces. Instead, they will focus on other parts of the face or look away. Yet despite being commonly recognized, this symptom is still not well understood.

"Why do autistic kids avert their gaze in the first place? What brain mechanisms are associated with that?" asks Davidson.

To address these questions, he and his colleagues, led by primary author of the study Brendon Nacewicz, combined magnetic resonance imaging (MRI) with an eye-tracking device that records where subjects are looking. This method allowed them to directly relate amygdala size with how much time the subjects spent looking at the eyes of pictured faces.

They found that autistic adolescent boys and young men who spent the least time looking at eyes had smaller amygdalae than normal males. A smaller fear center also correlated with difficulty distinguishing emotional faces from neutral faces and with parental reports of childhood behavioral impairment.

"The amygdala has a role to play in some of the symptoms of autism," says Davidson. For possible future therapies, he adds: "It provides an exciting target."

Much of Davidson's research is carried out at the [Waisman Laboratory for Brain Imaging and Behavior](#).



Richard Davidson

Growing Up With Autism

Teenagers and young adults are the emerging face of autism as the disorder continues to challenge science and unite determined families.

By Barbara Kantrowitz and Julie Scelfo

Newsweek

Nov. 27, 2006 issue - Chicken and potatoes. Chicken and potatoes. Danny Boronat wants chicken and potatoes. He asks for it once, twice ... 10 times. In the kitchen of the family's suburban New Jersey home, Danny's mother, Loretta, chops garlic for spaghetti sauce. No chicken and potatoes, she tells Danny. We're having spaghetti. But Danny wants chicken and potatoes. Chicken and potatoes. His 12-year-old sister, Rosalinda, wanders in to remind her mother about upcoming basketball tryouts. His brother Alex, 22, grabs some tortilla chips and then leaves to check scores on ESPN. His other brother Matthew, 17, talks about an upcoming gig with his band. Danny seems not to notice any of this. "Mom," he asks in a monotone, "why can't we have chicken and potatoes?" If Danny were a toddler, his behavior would be nothing unusual. But Danny Boronat is 20 years old. "That's really what life with autism is like," says Loretta. "I have to keep laughing. Otherwise, I would cry."

Autism strikes in childhood, but as thousands of families like the Boronats have learned—and thousands more are destined to learn—autism is not simply a childhood disorder. Two decades into the surge of diagnoses that has made autism a major public health issue, a generation of teenagers and young adults is facing a new crisis: what happens next?

As daunting as that question may be, it's just the latest in the endless chain of challenges that is life for the dedicated parents of children with autism. Twenty years ago, they banded together—largely out of desperation—to raise awareness of a once rarely diagnosed, often overlooked disease. They are united by the frustration of dealing with a condition that has no known cause and no cure. They have lobbied passionately to get better education for their kids and more money for research into autism, a neurological disorder characterized by language problems, repetitive behaviors and difficulty with social interaction. At the same time, more sophisticated epidemiology has revealed the true magnitude of the problem. Autism is now estimated to affect from one in 500 to one in 166 children—or as many as 500,000 Americans under 21, most male. That includes individuals with a wide range of abilities—from socially awkward math whizzes to teens who aren't toilet trained—but who all fit on what scientists now consider a spectrum of autism disorders.

The culmination of much of this parental activism is the Combating Autism Act, which was pushed by a collection of advocacy groups like Cure Autism Now, led by Hollywood producer Jon Shestack and his wife, Portia Iverson; Autism Speaks, started by Bob Wright, CEO and chairman of NBC Universal, and the Deirdre Imus Environmental Center for Pediatric Oncology. The bill unanimously passed the U.S. Senate in August but was blocked in the House by Texas Republican Joe Barton, chair of the House Committee on Energy and Commerce. In a September meeting, Barton told autism activists that he would continue to oppose their legislation, which earmarks \$945 million for research over the next five years, because it conflicted with his own proposal to reform the National Institutes of Health. As a result, autism advocates began inundating him with faxes and phone calls and lambasting him in the press. To advance the cause of research, radio host Don Imus joined in and pressured Barton on the air, calling the congressman, among other things, "a lying, fat little skunk from Texas."

Now that the Democrats have won the House, Barton will lose his chairmanship in January and NEWSWEEK has learned that he is attempting to pass a compromise version of the bill before then. If passed, the House bill would fund a new push for early diagnosis, which is critical to starting therapy as soon as possible. In a particular victory for parents, the legislation specifies that the research oversight committee should include at least one person with autism and a parent of a child with autism.

The House bill authorizes money for research into many questions, including whether environmental factors may trigger autism. One point of contention: the Senate bill mandated a specific amount of money for the NIH to research the role environmental factors might play in causing autism. But Barton resisted, and now the specificity about how much should be spent and where has been lost in the compromise version. Still, a Barton bill could come up for a vote as early as the first week in December and the legislation, says Alison Singer, the mother of a daughter with autism and an executive at the advocacy group Autism Speaks, "is

probably the single most important thing that could happen besides the cure."

A win in Washington may lift their spirits, but a legislative victory won't really change much for the Boronats and others like them. Some kids have made dramatic progress after intensive physical and behavioral therapy; many others still struggle with basic activities. Often, when lower-functioning young people reach 18, their parents will establish legal guardianship to protect them. But no matter what level they've reached, many will need help for the rest of their lives. Most government-sponsored educational and therapeutic services stop at the age of 21, and there are few residential facilities and work programs geared to the needs of adults with autism. "Once they lose the education entitlement and become adults, it's like they fall off the face of the earth" as far as government services are concerned, says Lee Grossman, president and CEO of the Autism Society of America, a major national-advocacy group.

According to the Harvard School of Public Health, it can cost about \$3.2 million to care for a person with autism over a lifetime. Caring for all persons with autism costs an estimated \$35 billion per year, the same study says. Families with limited financial resources are particularly hard hit. Other chronic diseases like diabetes are covered by insurance. But parents of youngsters with autism "have to navigate a maze and, if they find providers, then they have to figure out how to pay for it," says Singer. Grossman's early wish for the Combating Autism Act was that it would address the dire needs of autistic adults, and he drafted 30 pages of service-related issues. But that part was never introduced because a consortium of activists working on the bill concluded, for the sake of political expediency, that the bill shouldn't try to take on too much. In this light, restraint seems especially critical now, when the Iraq war has siphoned off so much federal money. "It's like a forest fire running through science and it burns a lot of trees down," says Dan Geschwind, a UCLA neurogeneticist. However, advocacy groups vow that the moment the bill passes, government funding for adult services will become their next priority. Wright believes there is substantial congressional support for this, possibly from Sen. Hillary Clinton.

Moving through adolescence to adulthood is never easy, but autism transforms even the most routine activities into potential minefields. Recognizing the norms of teen behavior can be a Sisyphean task. Helen Motokane's daughter, Christine, 14, has Asperger's syndrome, a high-functioning form of the disorder. She struggles to fit in at her Los Angeles public school—and that means hiding parts of her true self. One secret: she loves Barbie. "She knows it's not cool to wear clothes with Barbie logos, so she tries to keep that at home," says Helen, who gently prods her daughter into developing more mature interests. "She says, 'You're trying to make me grow up, aren't you? You want me to do all these things right away.' I go, 'No, no, no.' I reassure her that we're not trying to push her." But an hour or two later, her mother says, Christine will ask, "Is it OK if I like Disney Princess even though other kids my age don't like it?"

Keri Bowers of Thousand Oaks, Calif., says her son, Taylor Cross, 17, seems perfectly normal at first. But sometimes he'll just blurt out what he's thinking without any internal censorship. Passing a stranger on the street, he might say, "You're in a wheelchair!" "When you're socially odd, people are afraid," Bowers says. "They want to get away from you and cross to the other side of the street." Not surprisingly, Taylor had no friends at all in the public school he attends until he began to meet other teens with autism—young people his mother describes as equally "quirky."

In one way, he's not quirky at all. "He's attracted to girls," Bowers says, "but he's shy. He doesn't really know how to talk to them." A few months ago, he asked out a girl from his school who does not have autism but who had been friendly to him. Bowers had a psychologist friend shadow the couple at the movies. "Taylor only spoke about subjects he was interested in," Bowers says. "He wouldn't do a reciprocal back-and-forth conversation on topics about her." Still, when Bowers later asked if he wanted to kiss the girl, Taylor surprised his mother with his sensitivity. "He said, 'Yes, but she's very religious and I would never do that'."

As young people with autism approach adulthood, some parents can't help but feel the huge gaps between their child's lives and others the same age. "It's very hard, especially in our competitive society where people strive for perfection," says Chantal Sicile-Kira, whose son, Jeremy, 17, can communicate only by pointing to letters on an alphabet board. The San Diego resident hosts "The Real World of Autism With Chantal" on the Autism One Radio Internet station and wrote "Adolescents on the Autism Spectrum" (*Penguin, 2006*). Like many youngsters with autism, Jeremy finds new environments difficult. "If he walks into a new store," his mother says, "and there's horrendous fluorescent lighting, within 10 minutes I'll look down and he's starting to wet himself." Despite such challenges, Sicile-Kira plans to help Jeremy live on his own when he's an adult—perhaps rooming with another young person with autism.

Independent living is a major goal of many families and, with the help of therapy, thousands of youngsters who in earlier generations would have been consigned to institutions are now going to college and looking forward to a normal life with a job. But for every one who makes it, there are many more young people like

Danny Boronat, who has come so far and yet still faces much uncertainty. Once unable to utter a sentence, Danny now reads at a second-grade level, competes in the Special Olympics and willingly takes on household chores like loading the dishwasher. But he also can spend hours playing with water. He picks obsessively at his cuticles, and sometimes cuts himself (his mother tries to hide any scissors in the house). He has no close friends. Next year he'll turn 21 and will no longer be eligible for the workshop where he does simple assembly-line work three days a week. After that? No one knows, not even his parents. "It's terrifying," says his mother, who started her own charity called DannysHouse to focus on adults.

A few states like California and Connecticut, newly aware of the crisis, have launched efforts to meet adult needs. But until programs are widely available, families are left to cobble together a patchwork of solutions—from informal day care to hourly caretakers to private residential programs. But these are stopgap measures. Parents worry that they will run out of money to pay for these services—and that they won't be around forever to arrange them for their children.

It's understandable that these parents would feel distraught. Many adults with autism require so much special care that it's hard to imagine anyone but a loving family member willing to provide it. "My wife and I are concerned about what's going to happen to our son when we pass on," says Lee Jorwic, whose son Christopher, 17, is unable to speak even though he's been in therapy since childhood. At 6 feet 4 inches and 290 pounds, Christopher is "our gentle giant," his father says. But because of his disabilities, even the most routine tasks require extraordinary preparations. Two years ago, for example, Christopher got an eye infection. He couldn't sit still long enough for the doctor to perform an exam so he had to go under anesthesia twice "just so the guy could look in his eye," his father says. Grossman says the Autism Society gets hundreds of calls every day from families like the Jorwics. "The most distressing, most disheartening, are from parents of older kids, parents who are at the end of life," he says. "They've been fighting this all their life, and they don't have a place for the kid after they die."

The natural successors to parents as caretakers would be siblings. Some families feel that's too much of a burden; others say that's a natural part of life in a family with autism. When one sibling has autism, the needs of so-called neurotypical children may seem to come second. Beth Eisman of Potomac, Md., recently sent her oldest daughter, Melanie, 18, off to college. Her goal for her younger daughter, Dana, 16, is more basic: independence. Dana's tantrums limited the family's participation in Melanie's school activities. "The old days were pretty bad," Eisman says. "Melanie often took the brunt of it." Now that Melanie is gone, Dana feels the loss. Eisman says Dana often goes into her sister's room and says, "I want Melanie."

Many families are sustained knowing that, by raising awareness of autism, they have already given their children the gift of a meaningful identity. "If this was 10 years ago, my daughter's classmates might say she's the one who talks to herself all the time and flaps her hands," says Roy Richard Grinker, an anthropologist at George Washington University and father of Isabel, 15. "But if you ask these kids in 2006 about Isabel, they say she's the one who plays the cello and who's smart about animals." Inspired by his daughter, Grinker explored autism in different cultures for his book "Unstrange Minds: Remapping the World of Autism" (*Basic Books, 2007*). "The more peers of the same age group understand about autism, the more likely they are to be kind, caring and integrate them into community life."

Twenty years ago, that kind of acceptance was inconceivable. Autism was considered rare and few physicians understood it or were able to help. The disorder was first identified by Leo Kanner of Johns Hopkins in 1943. About the same time a German scientist, Hans Asperger, described a less severe form of the condition. But with the ascendancy of psychoanalysis in the postwar years, the predominant view was that autism was a psychological disorder caused by a lack of love from "refrigerator mothers," a term introduced by the controversial psychologist Bruno Bettelheim. In the 1970s, parents started pushing back against this theory and encouraging researchers to look for neurological causes. It wasn't until 1980 that autism became an official clinical diagnosis, separate from childhood schizophrenia or retardation. Since that time, as scientists have learned more, they have broadened the diagnosis to include a spectrum of disabilities. Now, they are re-evaluating it even further, considering the idea that there may be multiple "autisms."

As knowledge about autism spread in the 1990s, families began to get more accurate diagnoses for children who might in the past have been labeled mentally retarded or emotionally disturbed, and the number of cases skyrocketed. Because of the Internet and extensive networking, parents around the country found allies and became powerful and articulate advocates. Even longtime autism researchers say families have really led the way. "Beyond raising awareness," says Dr. Thomas Insel, director of the National Institute of Mental Health, "families have become the real experts on this disorder. They have to figure out how to cope with a child who becomes explosive, disruptive, who could have a meltdown at any moment. They become highly skilled at knowing what helps."

Autism has set all these families on a unique journey and, while the road ahead is still unclear, they cherish small triumphs along the way. Grinker has a Ph.D. from Harvard and, in his community, many parents dream of sending their children to the Ivy League. He and his wife, Joyce, a psychiatrist, know that Isabel will never join them. But raising Isabel has its own rewards. Isabel's sister, Olivia, 13, is "like a third parent," says Grinker. The family judges Isabel not by the standards of others but by how far she has come. "When Isabel achieves something, I feel like we're a team, like we all did it, and I feel incredibly rewarded," he says. For now, that is enough.

With Karen Springen and Mary Carmichael

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Landon's world: living and learning with autism

By Joy Swearingen, Managing Editor

Autism: A pervasive developmental disorder that occurs at birth or soon after. A prominent feature of autism is the inability to communicate in realistic or traditional ways.

That simple explanation has defined Robin Shipman's life for the past 23 years.

Ever since Robin learned that her firstborn son, Landon, was autistic, she has been immersed in learning, teaching and advocating about the condition. Landon has been growing, learning and sharing.

Robin has given up a career of her own to teach and care for Landon. She has created a home schooling curriculum for autism which she is sharing with others, and she has voiced her message of advocacy with U.S. senators.

In the process, Landon has thrived, now growing some produce and caring for animals in the mini-farm set up by his family at their rural LaHarpe home.

The diagnosis

The story began Dec. 20, 1981, when Landon was born in Iowa.

"By the time he was two, I started recognizing that something was not quite right. He acted like he was deaf, but he definitely could hear," Robin said.

"Verbal communication was a problem. We were not seeing the progress this young mom wanted." At three years, he could say three words: mom, dog, and applesauce. They had his hearing checked, and his tied-tongue was clipped.

"He had attachments to very strange things, like the vacuum sweeper, and he would fold wash cloths into complicated geometric shapes to put in the back of a toy dump truck." Landon had sensitivity to light and touch. He always smelled things.

When Landon was three and a half, he was diagnosed with autism at the University of Iowa Clinics in Iowa City, after a long series of tests. For one set of psychological tests, he stayed at the hospital without any contact with his family for two days.

"Those were dark days. The doctors shared with my husband and I that this was a lifelong



Landon Shipman and his mother, Robin, cuddle two of his white silky chickens. Caring for animals on his mini-farm is part of Landon's daily routine.

condition. They said, 'He and you would be better off to put him in a group home.' I said, 'Absolutely not!'"

During this time, Robin became acquainted with her "angel," Sue Baker, the Iowa autism consultant assigned to Landon. She guided them with information, and helped them understand how to best deal with Landon. By this time, Robin and her husband, Audie, had a second son, Brenton, two and a half years younger than Landon.

"Being the optimist I am, I poured myself into this. I went to the library - no internet back then - I was like a sponge soaking up all I could read," she said. "The doctors were so focused on what he couldn't do. For me failure has never been an option. It can't be, not when it relates to your child and his livelihood. You find the strengths, the things they can do and help them increase self esteem."

Educating Landon

Landon went to preschool. They started him in kindergarten, setting up his IEP (individual education plan) in a special education program.

"When the local teachers didn't know what to do, Sue came in," Robin said.

After a bad incident at the school, Robin withdrew Landon from school and contacted the state board of education for an approved curriculum for home schooling a child with autism. There was none.

So she worked with Baker to create her own. Focusing on what Landon could do became her mantra. By this time they had moved from Iowa to Wisconsin.

"I took Landon's strengths and accelerated them. For example math is typically hard for autistic children, but he loves to cook. Measuring in the kitchen, that wasn't math, it was fun, but he was working with fractions. I was elated," Robin said.

She started incorporating music, finding just the right piano teacher when he was nine.

"It brings enjoyment into his life. It's a positive," Robin said. He has played Christmas recitals at nursing homes and at Shopko. "People were touched with his humbleness. That's what Landon has been able to do."

Other points in her work with Landon have been to take advantage of his incredible memory.

He has sharp vision and hearing. Many concepts are best learned visually.

She initiated the STAR concept: Stop, Think, Act and Reward. These steps help Landon to focus on the task she wanted him to do. The reward was most often high verbal praise.

Many things become frustrating to an autistic child, or he can become overly stimulated because of the sensitivity to noise, light, etc. Two tools were used as Robin worked with Landon.

"A bean bag chair was instituted for when he would get frustrated, not as a 'time out' for discipline, but more as a method of relaxation and therapy. You could just see the frustration ease up," Robin said.

"Sometimes we would light a candle to release tension. We'd just stop what we were doing, relax and focus on the candle, watch the flame. After a while we would put it out and go on."

Throughout her education of Landon, Robin has learned the rules, used the rules and then broken the rules. Sign language, for example, is sometimes used because it is an easier way to

communicate than speaking.

"But I had a conflict with the school. I pushed speaking. I was afraid he would get lazy at verbal communication," Robin said.

Early on, developing a systematic routine is important in helping an autistic child.

"When he began to reach adolescence, I felt the need to vary his schedule. It was important that he could break that routine, because life is not like that. I'm not saying don't reinforce structure and routine, that's important. But I would spontaneously throw changes at him, maybe change piano lessons to a different day."

Robin has developed Landon's social skills with a home schooling and youth bible study groups.

Several manuals for autism and Augsbergers have been helpful, with ideas on how to maintain conversational skills. She runs through questionnaires asking him opinions on what foods he likes, etc.

During much of this time, Audie has had a job that took him away from home for weeks at a time. When his dad is at home, Landon works outside with him, gaining confidence with physical tasks.

"He would go with his dad working on private jobs, like tree trimming and hauling brush. Boating and fishing are a great love for our family. These outdoor things help him with self esteem, focusing on what he can do," Robin said.

As Landon has grown into adulthood, Robin continues to develop what he can do. They study language skills and work on daily life skills like cooking, cleaning and shopping with her.

The family purchased their farm home near LaHarpe about a year ago. As a family project, a small shed for calves, chicken house, and rabbit hutch were built. Landon lovingly cares for the animals, with a little guidance from his family. He raises pumpkins and gourds, and makes cider from the apples.

Landon describes his day

"In the morning, I get up early. I crack the eggs, whip them up and make a cheese omelet. I like cheese omelet," Landon said proudly. "Then I take care of the animals. Larry and Curly are the cows. I lead them to the stalls. I give them alfalfa hay. I feed my chickens. There are two roosters, and nine hens, Sadie, Dixie, Cotton Candy....."

Some of the chickens are white silkies with extremely soft, white feathers and a black beak.

"I love Buster," Landon said. Buster is a white Flemish giant rabbit. "I am a farmer," he tells visitors. "My brother is a police chief. My job is as important as his, because I keep these animals alive."

Landon likes to come up with long lists of rhyming words, and has a remarkable memory. With glee he rattles off a long, complicated tongue twister about the Fudnutter Brothers. Sunday afternoon is often time with his grandparents and cousins, where likely as not, he is the winner at board games and Uno Attack.

He continues with piano. His favorite tunes are Handel's "Largo" and "The Battle Hymn of the Republic."

"What is that song?" he asks and then quickly answers, "It is a patriotic song."

While autism often puts its carriers in a non-communicative, parallel existence with the people

around them, Landon is friendly and curious, greeting visitors: "My name is Landon Shipman. What is your name? How many children do you have? And what are their names? When was Jason born? Is he the oldest?"

Advocating for understanding

"Landon is our blessing; society's ignorance is really tough for us," Robin said. "For 25 years I've been trying to advocate by telling his story. Education is the first crucial step, the best remedy, the best tool."

Early on, Robin had cards printed which she or Landon could give people that might not understand his needs or actions when they were in public.

It read: "My child was born with autism. Please help to educate others. Use your local library and learn more. My son, Landon, thanks you." This message could change scorn or impatience into understanding and interest.

In Wisconsin, she stepped into the political arena.

"I was concerned with the lack of resources for families. He was not able enough to take on a sheltered job, but he was too high functioning for their workshop."

Congresswoman Tammy Baldwin from Wisconsin took the issue to Washington D.C. They also had an unexpected conversation with Sen. John Kerry.

"We were in a cheese shop in Wisconsin, when suddenly they were locking down all the doors. Sen. Kerry was there campaigning. We talked with his wife for a while, and then she told him to come talk with us. He listened to our concerns. We hope that they can give Congress a sense of direction on what's going on out here."

She has had teachers call and ask her to observe a student in their class, looking for traits that might be autism.

"It is important to help advocate, to help other families. I speak to parents who are at their wit's end. We are thankful to be there as an encouragement.

"Landon has come milestones from where he was when he was diagnosed. I'm a mom with a mission. I want other families of children with autism or other disabilities to know there is hope. I feel this is what I'm supposed to do," Robin said.

"It is not always easy, but hang in there. Be tenacious. Every day we're all a work in progress. We can have a pity party now and then, but then blow your nose and go on."

Robin welcomes communication through sshipman@winco.net or call 319/316-2402.