



TARC NEWSLETTER

Oklahoma's leading information source on issues impacting the lives of people with developmental disabilities and their families

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CONTENTS

Service for Individuals on the Autism Spectrum.....1-4

Proposal for Health Care Reform.....4-6

Cost of Living Adjustments.....7

New Professional Resource for Support7

Clinical Test for Medication.....8-9

Casting Light on Social Blame.....9

Accessibility.....10

Calendar of Events.....10

Services for Individuals on the Autism Spectrum What Does Oklahoma Need to Do?

By: John F. Gajda, TARC Executive Director

The release of information about two significant studies this October has prompted me to sit back and ponder the state of services for individuals on the autism spectrum. The first study is a report titled “Prevalence of Parent-Reported Diagnosis of Autism Spectrum Disorder among Children in the US, 2007” that is being published in the November edition of the journal Pediatrics. The study reports a prevalence of autism spectrum disorder among children that is higher than previous US estimates. Rather than 1 out of 160 or 1 out of 150 this study reports an incidence of 1 out of 100 children. The second report by the National Autism Center established a set of standards for effective, research-validated educational and behavioral interventions for children on the autism spectrum.

These studies are significant because they:

1. Indicate that we may have more children in Oklahoma on the autism spectrum than we have estimated in the past, and
2. There are some sound, proven intervention techniques that can benefit these children.

This is important because it has implications for planning a system of services in Oklahoma for individuals on the autism spectrum. I didn't have to search far for an evaluation of where Oklahoma currently stands.

“Making individuals with related conditions such as autism spectrum disorders eligible for services under a Medicaid community waiver is possible, it is being done in some states, but it is perceived to be a costly leap forward that Oklahoma cannot, at this time, afford. This fiscal gridlock leaves Oklahomans with autism spectrum disorders and their families in the biggest gap in our service system. The increased incidence of such individuals represents a policy and service challenge for our state. Filling the gap will require major collaboration among agencies and organizations in Oklahoma as well as an increase in funding. ...Increased awareness is important. But, in Oklahoma, as in many other places, what we really need is to move people with autism spectrum disorders out of the gap and into our service system. They have been waiting too long.”

“Autism – The Ultimate Gap”, published in the TARC Newsletter, April 2004

“Services” continued on pg 2

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TARC is committed to ensuring a high quality of life for Oklahomans with developmental disabilities through education, empowerment, support and advocacy. For additional information about TARC or to volunteer, contact us at:

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When I wrote these words, now over five years ago, I had hopes that Oklahoma would move forward and more people with autism would be incorporated into the formal service system. Reflecting on these words today I realize they could well have been written last week rather than in 2004 because they still represent the harsh reality for many people with autism spectrum disorders in Oklahoma.

We have talked a lot in the past five years about what needs to be done. There have been family listening sessions, legislative hearings and debates, an Interim Legislative Study and increased awareness about Oklahomans with autism spectrum disorders.

There are small pockets of progress such as the pilot preschool program for young children in Oklahoma City that currently serves only a handful of children. We have had a small pilot program that tested an approach to family support, but this effort was discontinued a year ago principally because there was no long term funding allowing it to grow. We now have an Oklahoma Autism Network based at the University of Oklahoma that helps and encourages parents and provides some leadership on issues. School systems throughout the state have also developed new programs to serve young children on the spectrum. All of these efforts though, are dwarfed by the growing unmet need, the numbers of people on the autism spectrum grow while services don't.

The inaction in Oklahoma is not due to a lack of focus. Over the years there have been many attempts to jump-start service development through specific recommendations.

The Individuals with Autism and Their Families Oklahoma Plan

In 2002 Director Howard Hendrick of the Department of Human Services (DHS) convened a task force, the Autism Working Group, which developed a vision statement, "The Individuals with Autism and Their Families Oklahoma Plan", for serving people with autism spectrum disorders in Oklahoma. As an outcome of this study DHS is now funding the Tolbert Center at the University of Oklahoma Health Sciences Center which operates The Oklahoma Autism Network. The mission of the center is to provide evidence-based information about autism and information about resources available in the state for Oklahomans with autism, their families and the professionals who support them. Due to limited funding, the current focus of the Oklahoma Autism Network is to build on the resources that already exist and

not to develop new services.

Policy Development Options for Families Affected by Autism: Meeting the Needs of Oklahomans

In 2007, to gain some perspective on the need for services in Oklahoma, the Oklahoma Developmental Disabilities Council, OKDHS Developmental Disabilities Services Division, and the Oklahoma Autism Network convened a round-table discussion on possible public policy development. Invited participants included parents of children with autism spectrum disorders, long-time advocates for persons with autism, and staff from the Oklahoma Department of Human Services Developmental Disabilities Services Division, Oklahoma Health Care Authority, and Special Education Services Section of the Oklahoma Department of Education.

Participants discussed and defined ideas that might provide meaningful services and supports for Oklahoma families. The findings were presented in a report to a Legislative Interim Study committee. Included below are the recommendations this group made.

1. Increase funding for SoonerStart services.
2. Expand mandatory, competency-based training opportunities for SoonerStart professionals and families related to Autism Spectrum Disorders.
3. Use SoonerStart as the vehicle for attracting additional professionals to the state who can diagnose ASDs and develop and implement intervention plans. One option would be a grant program to repay student loans for related service providers who work in SoonerStart early intervention or the public schools.
4. Fund an optional year of SoonerStart services, as allowed under IDEA, for those families that need specific, intensive services beyond 36 months.
5. Provide training to parents on their children's educational rights and their roles and responsibilities in developing appropriate IEPs for students with ASDs.
6. Assure the involvement of appropriate professionals in the fields of allied health, assistive technology, career or post-secondary education planning, and the like as students with ASDs advance in school.
7. Convene a task force on school-based services for children with ASD from among the members of the State Department of Education's IDEA-B Panel.
8. Fund training programs to be implemented throughout Oklahoma, developing specific trainings for rural areas of the state without the density of

"Services" continued on pg 3

Continued from pg 2

available support services.

9. Support the increased use of technology to deliver “remote” training, e.g. College of Direct Supports, currently implemented by OKDHS Developmental Disabilities Services Division.

10. As specialized schools for children with ASD are the focus of a Legislative Study Committee, keep in mind the significant number of Oklahoma families seeking social services beyond an individual’s “school age” years, and the need to advance the system as a whole.

11. Because dollars are scarce, expenditures should be directed toward therapeutic interventions, not toward “bricks and mortar.” The State Department of Education should assure that school superintendents are aware of the High Need Risk Pool and that policies allow for ease-of-access of these funds when necessary for the financial well-being of that school district and for the benefit of children in that school district with significant support needs.

12. While short-term solutions can be of immediate benefit, the more difficult, long-term solutions should also be considered.

13. ALL available funding streams, public and private, should be reviewed to determine which would provide children the most immediate access to services by qualified providers. Care needs to be taken with both public and private insurance to ensure that service expansion specifically targets early and easy access to autism services and minimizes any unintended consequences that could add to the cost. The provider shortage ensures reduced costs at the outset for either Medicaid services or private insurance.

14. Licensure law for BCBA’s should be developed so that Oklahomans can receive services from qualified providers, and payments to those providers can be Medicaid reimbursement-eligible.

15. The Legislative Interim Study Committee should contract with a mutually agreed upon consultant to do a study on costs, riders and potential tax credits to insurance providers that provide coverage to persons with autism, so members can have accurate information for decisions for the coming session.

16. Continue to research innovative ways to provide direct services and training for families and professionals.

17. Require child care licensing staff and child care directors to attend training on legal responsibilities of accepting children with disabilities, including

children with ASD, and how to address challenging behaviors.

18. Increase the special needs reimbursement rate.

19. Evaluate the weights used in rating facilities when complaints involve children with disabilities.

20. Discuss, implement, and market other incentives that will increase the number of child care centers willing and able to accept children with ASDs.

This study stated that “Oklahoma families remain largely unserved or underserved. The situation is critical, and will become more critical in the coming months and years. Oklahoma children are being diagnosed with autism spectrum disorders at higher and higher rates. At the other end of the spectrum are adults with autism who live at home with aging parents, languishing and isolated, without community supports or services – or a plan for what will happen when their parents are no longer able to provide care. Well-trained professionals who can provide therapeutic services are in limited supply, and few families or school systems can afford the intensive therapeutic needs of this growing population. These problems will continue to grow and continue to burden established social service systems.” For more information on this study, contact Ann Trudgeon, the Director of the Oklahoma Developmental Disabilities Council at 405.521.4984 or Ann.Trudgeon@okddc.ok.gov

Results of the National Standards Project

One of the barriers to advocacy for services in Oklahoma has been questions about what the effective forms of treatment are. Any doubts about which services are appropriate for individuals on the autism spectrum were recently addressed by the report I cited in the opening paragraph of this article. The National Autism Center has completed an unprecedented multi-year project — the National Standards Project — to establish a set of standards for effective, research-validated educational and behavioral interventions for children on the spectrum. These standards identify treatments that effectively target the core symptoms of ASD. The resulting “National Standards Report” is the most comprehensive analysis available to date about treatments for children and adolescents with ASD. It is a single, authoritative source of guidance for parents, caregivers, educators, and service providers as they make informed treatment decisions. As I read through a copy of this report I couldn’t help but get encouraged by this excellent report. It listed specific “Established” Treatments that produce beneficial out-

“Services” continued on pg 4

Continued from pg 3

comes and are known to be effective for individuals on the autism spectrum.

The 11 Established Treatments specifically mentioned were:

- Antecedent Package;
- Behavioral Package;
- Comprehensive Behavioral Treatment for Young Children;
- Joint Attention Intervention;
- Modeling;
- Naturalistic Teaching Strategies;
- Peer Training Package;
- Pivotal Response Treatment;
- Schedules;
- Self-management; and
- Story-based Intervention Package.

This report also outlined 22 “Emerging” Treatments that have some evidence of effectiveness, but not enough to be confident that they are truly effective.

Finally it listed 5 “Unestablished” treatments for which there is no sound evidence of effectiveness, although there is no way to rule out the possibility these treatments are ineffective or harmful.

Providing details from this report is beyond the scope of this article. My point is to highlight this pivotal work and direct those interested in the full report and details about each of these treatments to the website of the National Standards Project at www.nationalautismcenter.org where a copy of the summary and full report can be downloaded.

Conclusion

I thought about an appropriate ending for this commentary. I decided that, as I began, I need to go back to my 2004 article when I concluded:

“Like many other issues in Oklahoma though, funding is an issue... Meeting the needs of people with autism spectrum disorders is a much different problem than the unserved with developmental disabilities currently on the waived service waiting list. For many of those in need who do not have a secondary diagnosis of mental retardation, providing services requires a major change in current service eligibility. Making individuals with related conditions such as autism spectrum disorders eligible for services under a Medicaid community waiver is possible, it is being done in some states, but it is perceived to be a costly leap forward that Oklahoma cannot, at this time, afford.

This fiscal gridlock leaves Oklahomans with autism spectrum disorders and their families in the biggest gap in our

service system. The increased incidence of such individuals represents a policy and service challenge for our state.... Increased awareness is important. But, in Oklahoma, as in many other places, what we really need is to move people with autism spectrum disorders out of the gap and into our service system.”

We have much more knowledge and evidence than we did five years ago about what we need to do in Oklahoma for individuals on the autism spectrum. Except for a few examples that impact a small number of people we have done nothing to close the gap I referred to in 2004. The problems have not gone away, they have only increased in magnitude. As the Center for Disease Control suggests, we need to make autism spectrum disorders a public health priority and work to implement the recommendations we have cataloged.

A Proposal for Preventing Health Care Reform from Burdening Our Country

By Stephen F. Gold, Esq.,

An attorney in Philadelphia who specializes in disability



The following is intended to add some humor to the current debate on health care reform in the hope that the humor might lead to some rational decision-making. Perhaps that is too much to wish for.

A Proposal for Preventing Health Care Reform from Burdening Our Country

Every day 14,000 Americans lose their health coverage. More than 46 million people are without health care. But maybe many of these people really do not deserve and should not receive health care. Just because someone is poor or ill or disabled does not mean he or she deserves health care.

Similarly, many of the remaining millions of people who are already paying for private health insurance or are receiving publicly funded health care do not deserve the benefits they take for granted.

We must cut costs and the only fair way is to deny

“Reform” continued on pg 5

health care to all people who do not deserve to receive it. Throughout the current health care debate, we have worn blind folds. In darkness, we have each touched a part of the health crisis, like the elephant's tail, trunk, or ear. Based on what we touched, we thought we understood the problem and had the answers.



But just feeling up part of the animal is not enough. The trick is to figure out how we decide who really should not receive health care. Who is unworthy of receiving it? How we can persuade them not to request or receive health care? Once we figure this, we will significantly reduce our health costs.

The goal: Increase the number of people among us who should not receive health care because they are not worthy.

We have assumed that there is a health care crisis because of the health care insurance companies, the pharmaceutical drug companies, the doctors and hospitals, and the lawyers. But these folks represent only part of the trunk and the elephant's left front foot.

No, the cause of the health crisis is much bigger. It's them - those people who do not deserve unlimited health care - for themselves, for their children, for their parents.

Let's look at some categories of them, where we might be able to increase the number of people who should not receive health care, leaving more for the deserving ones.

The Oldest People

In this category are people over 90 and maybe even over 85. But the years are not the crucial criterion. We know that in the last year or two of their lives is when most health care funds are expended per person. Health care in these years is extremely expensive, and for what? A few more years. A few years of what? Visiting doctors and hospitals? Pain, worry and discomfort? Cost?

Most older people want all the health care that exists, and if it doesn't exist, it should be invented. Don't discuss costs. Ask this group if they deserve to receive unlimited medical care and bankrupt the rest of the country for their health care and they'd not flinch - "we earned it." Well, maybe many of them did not pay into the system anywhere near what they'll get out of it, but why quibble. And anyhow, the deserve equation is not

just a money-in/money-out calculus.

These older geezers sound like they're against any change. So what would they accept?

Here's a deal that many seniors might accept, and will save trillions in medical costs. When your doctor thinks your last few years have arrived, you become eligible for a month or maybe two of free room, board and transportation to anywhere in the continental USA. If your doctor believes that these last few years could be especially expensive medically, then we'll consider Alaska, Hawaii, and Puerto Rico. If the old person will agree to a three year program, then we'll provide a free two month cruise and funeral expenses. In exchange, the senior must agree to forego any non-routine medical care for the number of years bargained for. Pain medications will be provided gratis.

The "Preventable Chronic Disease" People

The following people should be denied health care because their diseases are their own fault. Given modern medicine's advances in genetics, if a person can genetically establish "no fault," then we'd give them a pass.

The Obese People

Now we all know that anyone who really wants to control their weight can do so. There is no excuse for people stuffing their faces with greasy hamburgers and french fries, or drinking soda with all the added sugars. If they eat like that, why should they expect our health care system will cover them? Stuffing oneself should have consequences.

Isn't it time we stopped blaming the food industries that just want to make money? Attempts to change consumer eating patterns have failed. Therefore, let them eat whatever and however much they want, as long as they agree to live with the consequences and we don't have to pay their health care.

OK. Obese People have heard of the deal we made with our grandparents and even though they might not deserve it, let's see if we can make a deal, so we can save medical costs. We agree to pay for one year in a gym of your choice. In return, unless you lose by the end of the year an agreed on number of pounds, you will receive no medical care for the next two years that can be related in any way to obesity.

Shouldn't the same principle apply to children who are obese? It's never too early to deny health care to a

"Reform" continued on pg 6

kid who keeps eating and does not exercise. Let them learn early in life that there is no free health ride; suffering will benefit them later in life, if they survive.

But since parents are in control of what their children eat, or at least are supposed to be, then parents of obese children should also be punished and denied health care for themselves. It's also never too early to make parents act like adults.

The Smoking People

Smoking has been a recognizable cause of "preventable chronic diseases" for many decades. Since this has been known for many years, we should "just say no." Sorry. You smoked knowing the potential adverse effects and now you want us to pay for your choices? You've got to be kidding. No deals.

The No Immunizations People

These parents are a real problem because their choice not to have their children receive immunizations affects their kids, who have no say in the matter. If their children come down with a preventable disease, maybe the only option is to take their children from them, involuntary relinquishment of parenthood, and then we treat the children. Harsh, sure, but what are the options?

The Avoidable and Unnecessary Hospital People

Hospital costs make up the bulk of the health care system. Sure, many people need and deserve to receive care in a hospital, and the present proposal will not impact them. But what about people who do not manage routine conditions that with minimal proper care will avoid hospitalizations? For example, people with asthma or bacterial pneumonia often just don't follow their doctors' rules. They don't use their asthma inhalers, don't refill prescriptions on time. Then why pay for their hospitalizations? In this group, let's not forget those No Helmet People and the Car Drivers Above Speed Limit People. No medical care for their follies.

The Hypocrite People

Let's not forget those federally elected officials (and other federal employees and their families) who use and accept a publicly funded, single payer health system that they agree is the best. Yet, among them are elected officials who fight against any public option for the rest of us. Have they forgotten the Golden Rule? These officials should either entirely relinquish theirs and their

family's public option health benefits, or let the rest of us share the benefits.

Our senior citizens, who have worked so hard and long, receive Medicare health insurance, another public option. They want to keep their public health care and are afraid that if non-seniors had a similar option, then their Medicare benefits might be reduced. They want to keep what they have. The seniors should be told that they taught us as children to share our toys with other children, and yet now they forget their teachings. They too should be reminded of the Golden Rule.

The Oldest People, The "Preventable Chronic Disease" People, The Obese People, The Smoking People, The No Immunization People, the Avoidable and Unnecessary Hospital People, and especially the Hypocrite People, under my plan these folks will do fine without health care, and anyway, they don't deserve it.

OK Policy Releases Online Budget Guide

Unique reference and learning tool illuminates Oklahoma taxes, services, and fiscal outlook.

Oklahoma Policy Institute released its Online Budget Guide, a comprehensive look at how Oklahoma state and local governments collect and spend money to provide public services. According to Matt Guillory, Executive Director, "We've designed the Guide to be a resource for anyone interested or affected by government finance in Oklahoma. Those just getting interested will find it to be a clear and simple overview, but it will also serve as a great reference tool for legislators, advocates, members of the media, teachers, and others with greater experience in budget issues."

The Online Budget Guide adds to available information on Oklahoma's fiscal picture in several ways, including:

1. It includes taxes and spending of both state and local governments.
2. It looks more broadly at spending than just state appropriations to examine spending from all sources, including user fees and federal grants.
3. It uses key performance indicators to measure "what we accomplish" as well as "what we spend."
4. It takes an in-depth look at fiscal challenges state and local governments will be facing in the coming years.

"Policy" continued on pg 7

Continued from pg 6

Because it is online, the Guide has many advantages over a printed version, including regular updates as new data are available, so users can always have the most current information.

The Guide is available at <http://www.okpolicy.org/online-budget-guide> and the “Talking Points Version,” is also available for download which includes thematic and data highlights in just a few pages.

Source: OK Policy

Cost of Living Adjustments (COLAs)



The Social Security Administration announced that monthly Social Security and Supplemental Security Income (SSI) benefits will not automatically increase in 2010 because there was no increase in the Consumer Price Index from the third quarter of 2008 to the third quarter of 2009. This will be the first year without an automatic COLA since they went into effect in 1975. In the SSI program, the maximum federal payment for an individual will remain at \$674 per month. For couples, the maximum federal payment will remain at \$1,011 per month. SSI resource limits will remain at \$2,000 for individuals and \$3,000 for couples.

However, some changes will take effect in January in areas that are not tied to the COLA adjustment, including an increase in the substantial gainful activity (SGA) level for people with disabilities and an increase in the amount of earnings required to earn quarters of coverage, or work credits. The SGA level is used in determining whether an individual is disabled. The SGA level for people with disabilities will rise from \$980 per month in 2009 to \$1,000 per month in 2010. The SGA level for people who are blind will remain at \$1,640 per month in 2010 because it is tied to the COLA adjustment. Quarters of coverage are used to determine whether an individual has contributed enough to the Social Security system to be eligible for disability, retirement, and survivor benefits. The earnings needed to earn a quarter of coverage will rise from \$1,090 in 2009 to \$1,120 in 2010. For more details, see SSA's website: <http://www.ssa.gov/pressoffice/pr/2010cola-pr.htm>.

Source: Social Security Administration

New Professional Resource Establishes Ground-breaking Paradigm To Support People with Intellectual Disabilities

Society's labels have consequences. A bad credit score means you pay more for a loan. Careless driving that translates into several points on your license labels you a risky driver. But no label damages more than being called “mentally retarded.”

Setting aside that label and establishing the means to integrate people with intellectual disability into society based on their abilities rather than their deficits are the fundamental objectives of a new resource for professionals working with people with intellectual disabilities. The new resource, the 11th edition of *Intellectual Disability: Definition, Classification and Systems of Supports*, known in the field as the “Definition Manual” is published by the American Association on Intellectual and Developmental Disabilities (AAIDD).

“We understand that people with intellectual disabilities face enough challenges every day that they don't need to deal with a pejorative label. And as medical, educational and legal professionals, we know that mental intellectual disability is far more complex than a low score on an IQ test,” said AAIDD president Joanna Pierson, PhD, Executive Director of The Arc of Frederick County, MD. “The definition manual represents the most current thinking on how professionals should approach those with intellectual disabilities and offers tools and strategies to implement progressive services and strategies in various settings such as schools, provider agencies, and the policy world.”

AAIDD is committed to setting aside labels and instead focus on creating and supporting the services people with intellectual disability need to function fully in our society. AAIDD is committed to including the people with intellectual disability within every aspect of our lives whether they ride the bus with us, work in the same offices or play with our children.

To this end, the 11th edition establishes an advanced paradigm that professionals will use when evaluating and delivering the support services that a person with intellectual disability needs at school, at home, in the physician's office or the courts, if the need arises. Rather than look at individual deficits, this model is based on evaluating the support services someone needs to

“Resource” continued on pg 8

Continued from pg 7

reduce the mismatch between a person's capabilities and skills so that they can participate fully in all aspects of daily life.

Uniform criteria are included in the 11th edition that should be used to diagnose intellectual disability, including a combination of age of onset, IQ, and adaptive behavior skills. Several states now use different standards, ranging from IQ scores to a combination of IQ and certain skills. The 11th edition also contains the latest thinking, tools and strategies to diagnose whether a person has intellectual disability or not. The 11th edition is designed to be an invaluable resource for many professionals, including:

- Physicians may consult the guidelines to more precisely diagnosis a child or adult, such as evaluating the role of IQ in making a diagnosis and assessing how the individual is adapting to life's challenges and opportunities.
- Teachers and school psychologists at both the secondary and post-secondary levels can refer to sections when determining eligibility for special education services and how the AAIDD paradigm and IDEA (Individuals with Disabilities Education Act) are related.
- University and college faculty and students in medicine, special education and psychology disciplines can use the manual as a key reference in developmental disability.
- Those involved in the civil and criminal justice system can use the 11th edition when considering how the court should handle criminal cases involving an individual with intellectual disability.

Written by a committee of 18 experts, the 11th edition is based on seven years of work to synthesize current information and best practices regarding intellectual disability; reviews and critiques of the previous edition and feedback from the field. To download an FAQ on the AAIDD Definition Manual, visit <http://www.aaidd.org/media/PDFs/11eFAQ.pdf>. To purchase the book visit, <https://bookstore.aaidd.org/BookDetail.aspx?bid=97>.

Source: AAIDD

SAVE THE DATE

2009 Celebration of Advocacy

The 19th Annual Advocacy Awards and Annual Meeting will be on Monday, December 7, 2009

We hope to see all of you there as we recognize the amazing advocates and volunteers of 2009.

CLINICAL TESTS BEGIN ON MEDICATION TO CORRECT FRAGILE X DEFECT



NIH-supported scientists at Seaside Therapeutics in Cambridge, Mass., are beginning a clinical trial of a potential medication designed to correct a central neurochemical defect underlying Fragile X syndrome, the most common inherited cause of intellectual disability. There has to date been no medication that could alter the disorder's neurologic abnormalities. The study will evaluate safety, tolerability, and optimal dosage in healthy volunteers.

The work is the outcome of basic research that traced how an error in the fragile X mental retardation gene (FMR1) leads to changes in brain connections, called synapses. The changes in turn appear to be the mechanism for learning deficits in Fragile X syndrome. The new trial tests Seaside Therapeutics' novel compound, STX107, that selectively and potently targets the synaptic defect.

Fragile X syndrome is the most common inherited cause of intellectual disability, affecting an estimated 1 in 4,000 males and 1 in 6,000 females.

The syndrome causes a range of developmental problems, including learning disabilities and cognitive impairment. People with Fragile X syndrome may have anxiety and attention deficit hyperactivity disorder. About one-third of males with Fragile X syndrome also have autism or autistic-like behavior that affects communication and social interaction. Usually, males, who have only a single X chromosome, are more severely affected than females

People with Fragile X have DNA mutations in the FMR1 gene that, in effect, turn off the gene. Research in recent years by Dr. Bear and colleagues has identified the molecular consequences of this silencing of FMR1. Normally, the protein product of the FMR1 gene acts to dampen the synthesis of proteins at synapses that are stimulated via a specific class of receptors on brain cells--metabotropic glutamate receptors (mGluRs). Without the brake provided by FMR protein, synaptic protein synthesis is excessive and connections do not develop normally.

The current study will focus on a compound, des-

"Fragile" continued on pg 9

Continued from pg 8

ignated STX107, that selectively inhibits one type of mGluR receptor, mGluR5. Evidence in mice with Fragile X-like symptoms suggests that reducing levels of mGluR5 can restore normal synaptic protein synthesis and improve function.

The initial phase 1 study of STX107 will involve healthy volunteers. If results suggest that the medication is safe and tolerable, the study will progress to a phase 2 test of dosage and efficacy in adults with Fragile X syndrome. If STX107 shows promise in adults, the compound will be assessed for pediatric safety (with funding from the Best Pharmaceuticals for Children Act [<http://bpca.nichd.nih.gov/about/index.cfm>] through NICHD) prior to initiating clinical trials in children.

For more information on clinical trials related to Fragile X syndrome, go to <http://clinicaltrials.gov/>.

Source: National Institute of Health

Casting Light on Social Blame

Mothers whose children suffer from emotional and behavioral disabilities say they shoulder a tremendous social burden of responsibility to remedy their kids' problems, says Linda Blum, associate professor of sociology and anthropology at Northeastern University.

Over the past few years, Blum, an ethnographer whose scholarship focuses on gender, family and social inequality, has conducted scores of interviews among New England mothers raising children with so-called invisible disabilities, like attention-deficit and attention-deficit hyperactivity disorder (ADD/ADHD) and Asperger's Syndrome.

Neuroscientists believe that physiological differences in the brain are the most likely cause of such disabilities, from bipolar disorder to dyslexia. Nevertheless, Blum found that the mothers report they are frequently blamed and stigmatized by family and friends, doctors and school officials, as much as their children are by peers. Her findings held true regardless of race or socioeconomic status.

Parts of Blum's field study have appeared in the journal *Gender & Society*, and a book—Blum's third—is in progress. "Mothers are held responsible to do all this work to resolve their child's issues even if they aren't seen as the primary cause of the problem," Blum explains. "While it is accepted that the problems are

neurochemical or in brain imbalances, they are seen as no less responsible in the sense of going through all these efforts to find every possible service, treatment or specialist to resolve the issue."

Even moms of the highest social standing—those who are college educated, happily married and living in the most affluent communities—struggle to stand up to unrelenting criticism by neighbors and family members who question their parenting, Blum notes.

"Women who are in many ways so close to the idea of a good mother often torture themselves with thoughts of 'What should I have done differently,' or 'If I had only done this,'" she says. And since ADHD, for example, or Asperger's, are not well understood, mothers face a barrage of conflicting advice, particularly surrounding the burgeoning use of an array of psychoactive medications.

"Mothers are dealing with the scary decision of whether or not to give psychopharmaceutical medications to their children," Blum says. "That's not easy to deal with under any circumstances."

Moms on the other side of the socioeconomic spectrum face an additional set of challenges, Blum says. For those living paycheck to paycheck, picking from a myriad of mental health professionals, paying for private schools or hiring educational consultants are simply not options.

The nationwide surge in wealth, educational and occupational inequalities, along with shrinking government budgets for social services, health care, and education, are making it more difficult for mothers of even moderate means to secure help for their children, she adds.

What's more, single mothers of children with these disabilities report struggling to earn the respect of health professionals and school officials because of their unmarried status. One single mom told Blum that she has had to "advocate 5,000 times harder" for her child than if she was married.

Blum hopes her research illuminates the plight of women and their families and helps frame these issues as social problems rather than those of the individual. "I want to make visible aspects of women's lives that are being swept under the rug," she explains. "Society often blames the individual and fails to look at the more embedded problems that the individual should not be held responsible for."

Source: Northeastern University Office of Marketing and Communications

Accessibility

After four years of litigation, the Disability Rights and Education Fund (DREDF) and its co-counsel, head to trial on behalf of the American Council of the Blind (ACB) and a class of 3,000,000 blind and visually impaired plaintiffs. In a class action lawsuit filed under Section 504, plaintiffs are challenging the Social Security Administration's (SSA) failure to provide its communications in alternative formats that would enable people with visual impairments to have equal access to the agency's programs. SSA's failure to provide alternative formats has resulted in the loss of critical benefits, privacy and dignity for individuals who depend on Social Security benefits. The trial is in the US District Court for the Northern District of California in San Francisco and is expected to last for about two weeks.



Learn more about TARC by visiting our website at www.ddadvocacy.net

Not a member of TARC? Join Today!

A membership envelope is enclosed, we encourage you to become a member by filling it out and sending it back to TARC with your membership fee.

TARC is a network of programs advocating for Oklahomans with developmental disabilities. Your membership allows TARC continue providing the vital programs that help ensure a high quality of life for people with developmental disabilities.

TARC CALENDAR OF EVENTS

The Sapulpa Group has decided to discontinue their monthly support group but please take advantage of our other Mom's and Dads Group in Tulsa. If you have any questions please contact Sherilyn Walton, 582-8272

links | to support, to information, to friends.
Support Group for Adults with Asperger's Syndrome

Next Meeting:
Wednesday,
December 16th
6:30-7:45 p.m.

**The next meeting will be held at TARC's new office:
2516 East 71st St., Suite A
Tulsa, OK 74136-5531**

Links is a support group for adults with Asperger's Syndrome. Contact Amie Farinella, 918-582-8272 for more information.

Day Makers Activities group for adults with developmental disabilities
Contact: Amie, 918-582-8272

Tuesdays • 10:00-11:00 a.m.
Gatesway Foundation-Mabee Gym
1217 E. College in Broken Arrow

Thursdays • 1:00-2:30 p.m.
McClure Recreation Center
7440 E. 7th Street in Tulsa

Hispanic Parents Support Group
El Grupo Hispano de Apoyo a Padres de Familia
Next Meeting: Monday, November 30th
7:00 to 8:30 p.m.
St. Thomas Moore Catholic Church,
2720 S. 129th E. Ave., Tulsa

iJUNTOS!
Support Group for Hispanic Families

Contact Zaida at 918-582-8272 for more information.

Families in Transition

Families in Transition is a support group for parents of adult children with developmental disabilities.

**Contact Amie Farinella, 918-582-8272
For more information about the next meeting**

Connections Asperger's Group

There will be NO meeting in November
Instead join us in December

Wednesday, December 2nd 4:30 p.m.
Hardesty Library, 8316 E. 93rd St.

The "Connections" Asperger's Group is a social skills group for adolescents and young adults with Asperger's Syndrome. The group meets monthly. Contact Sherilyn or Amie at 918-582-8272 for more information.

MOMS & DADS SUPPORT GROUP

There will be no November Meeting.
Instead join us on
**Thursday December 3rd
7:00 pm-9:00 pm**
Kirk of the Hills,
4102 E. 61st St, Tulsa

The mission of the Moms & Dads Support Group is to nurture and support families whose children have a developmental disability, to encourage positive strategies in dealing with challenges, and to share in the joys of raising our children.

For more information, contact Sherilyn, 918-582-8272

1ST TULSA PEOPLE FIRST
Tulsa People First

**Help Shop for Project Elf!
December 5th**

**please contact Amie Farinella to RSVP
918-582-8272**